CULTURAL BELIEFS TOWARDS DISABILITY: THEIR INFLUENCE ON REHABILITATION.

Tseleng Leonea Masasa

Thesis presented in fulfillment of the requirements for the degree of

Master of Physiotherapy at the University of Stellenbosch

Supervisors: Mrs M. R. Faure

Ms. S. H. Irwin-Caruthers

March 2002

DECLARATION

I, the undersigned, hereby declare the work contained in this thesis is my own original work and that I have not previously submitted it in its entirety or in part at any university for a degree.

Signature: .....

Date: .....

ABSTRACT

South Africa is a multicultural, multiracial and multilingual nation ("the rainbow nation") with different traditions, values and cultural practices. Due to this diversity there are different belief systems, which give rise to different attitudes and practices towards various health issues such as disability, which in turn, have an impact on the rehabilitation of people with disability. The purpose of this study is to investigate the knowledge, attitudes and cultural beliefs towards disability and to identify the commonalities and differences of three broad cultural groups of South Africa (Blacks, Coloureds and Whites), and to determine their influence on the rehabilitation of disabled people in the Cape Town area.

Sixty respondents (20 Blacks, 20 Coloureds and 20 Whites) were interviewed utilizing the knowledge, attitude and belief (KAB) survey in the form of a structured interview. Both probability and non-probability (systematic and purposive) sampling were used. The study was carried out using both quantitative and qualitative methods.

The results showed that Whites and Colored generally had a fairly good knowledge of disability and its causes, acquired while they were young, whereas Blacks had a more superficial knowledge of disability, which was only acquired after the birth of a disabled child. The results also revealed that quantitatively all the cultural groups held positive attitudes towards the rehabilitation, education, marriage, childbearing and employment of people with disability. Attitudes towards the stigma attached to being disabled were also encouraging.

In contrast, the qualitative data showed disparities between the three cultural groups in attitudes towards rehabilitation, education and marriage. Although rehabilitation is considered an important aspect to disabled people and their families, some Blacks experience problems in transporting their children to centres where rehabilitation services are offered. Socio-economic factors also have a bearing on this.

The results revealed a general lack of awareness of disability among school children and teachers in Black and the Coloured schools, which may make it difficult for disabled children to be integrated into mainstream schooling.

Marriage and childbearing was regarded as a way of increasing the support base of individuals with disability in the Black group, while the Coloured and White groups viewed marriage as a way of enjoying life and having children a matter of individual choice.

Concerning employment and the promotion of people with disability, all three groups believed that disabled people have a right to be employed and earn a salary.

In the area of beliefs, the results showed that the Black group blamed disability on witchcraft and that they consult health professionals, folk healers and look to God for healing. Most of the Whites and Coloureds believed that disability is a result of natural causes, human error or the will of God.

There is an uneven geographic distribution of information about disability. Cultural beliefs towards disability may delay or hinder early identification of children and intervention.

Two main recommendations are made arising from these results. Firstly, health professionals should know and understand the culture, values, beliefs and expectations of their clients and, more importantly, bring services to the recipients in their own familiar environment, culture and community, via the CBR model.

Secondly, I recommend that an evaluation of knowledge and attitudes towards disability should be done in schools, where the disability awareness has been raised by some NGOs as compared with those where no intervention has taken place. A survey of this kind should be done in all the provinces of South Africa.

The findings from this research thus have very serious implications for the provision of inclusive education and quality rehabilitation services for all the disabled children of South Africa.

ABSTRAK

Suid-Afrika het 'n multi-kulturele, veelrassige en veeltalige bevolking ("die reënboog nasie") met uiteenlopende tradisies, waardes en kulturele praktyke. Hierdie diversiteit gee aanleiding tot verskillende sienswyses en praktyke met betrekking tot gesondheidskwessies soos gestremdheid, wat op gestremde persone 'n impak het. Die doel van hierdie studie was om die kennis, sienswyses en kulturele opvattings rakende gestremdheid by die drie breë kulturele groepe van Suid-Afrika (Swartes, Kleurlinge en Blankes) te ondersoek en te bepaal wat die verskille en ooreenkomste is en hoe dit die uitkoms van rehabilitasie van gestremde persone in die Wes-Kaap raak.

Sestig respondente (20 Swartes, 20 Kleurlinge en 20 Blankes)is tydens gestruktureerde onderhoude ondervra. Die "Knowledge, attitude and belief" (KAB) onderhoud is gebruik. Beide 'n waarskynlikheids en nie-waarskynlikheids steekproef en 'n kwantitatiewe en kwalitatiewe ondersoekmetode is vir die studie gebruik

Die resultate het getoon dat Blankes sowel as Kleurlinge 'n redelike goeie kennis het van gestremdheid en die oorsake daarvan, wat reeds op 'n jong ouderdom opgedoen word. Daarteenoor het Swartes gewoonlik 'n meer oppervlakkige kennis van gestremdheid, wat eers na die geboorte van 'n gestremde kind verwerf word. Kwantitatief is getoon dat al die kultuurgroepe 'n positiewe houding het teenoor rehabilitasie en onderrig van, huwelik met, hê van kinders en indiensneming van gestremdes. Houding teenoor die stigma gekoppel aan gestremdheid was ook bevredigend.

In teenstelling hiermee het die kwalitatiewe data ongelykheid tussen die drie kultuurgroepe getoon in houding teenoor rehabilitasie en onderrig van en huwelik met gestremdes. Swartes beskou rehabilitasie as belangrik vir die gestremde sowel as die familie, maar ervaar probleme met toeganklikheid tot rehabilitasie. Sosio-ekonomiese faktore impakteer hierop.

Skoolkinders en onderwysers in Swart en Kleurlingskole toon 'n algemene gebrek aan bewustheid van gestremdheid, wat integrasie in die hoofstroom-onderwys kan bemoeilik.

Die Swart groep het huwelik met en hê van kinders beskou as 'n manier om die ondersteuningsnetwerk van die gestremde uit te brei, waarteenoor die Blanke en Kleurling groepe die huwelik beskou as 'n manier vir die gestremde om die lewe te geniet en dat die hê van kinders 'n individu se keuse is.

Al drie die groepe glo dat die gestremde die reg het op indiensneming en om 'n salaris te verdien.

Sover dit die sienswyses oor gestremdheid betref, blameer die Swart groep die toorkuns daarvoor en besoek hulle die tradisionele geneser sowel as professionele gesondheidswerkers. Hulle verwag genesing van God.. Blankes en Kleurlinge glo dat gestremdheid die gevolg is van natuurlike oorsake, menslike foute of die wil van God.

Daar was ongelyke geografiese verspreiding van inligting oor gestremdheid. Kulturele sienswyses oor gestremdeheid mag 'n remmende invloed hê op op vroeë identifikasie en intervensie by kinders.
Twee hoof aanbevelings kan op grond van die resultate gemaak word. Eerstens behoort professionele gesondheidswerkers ingelig te wees oor die kultuur, waardes, sienswyses en verwagtinge van hul kliënte, en dit te verstaan. Dienslewering behoort na die ontvangers se eie omgewing, kultuur en gemeenskap via die GBR-model gebring te word.

Tweedens beveel ek aan dat 'n evaluering van kennis en sienswyses, rakende gestremdheid, in skole gedoen word. 'n Vergelyking kan getref word tussen die skole waar bewusmaking van gestremdheid reeds deur NRO's gedoen is, teenoor die waar geen intervensie was nie. So 'n ondersoek behoort in al die provinsies van Suid-Afrika uitgevoer te word.

Die uitkoms van hierdie studie het dus implikasies vir beide die voorsiening van inklusiewe onderrig en kwaliteit rehabilitasie-dienste vir al die gestremde kinders in Suid-Afrika.

DEDICATION

THIS THESIS IS DEDICATED TO MY LATE FATHER

MICHAEL SENNA MASASA

WHO DIED WHILE I WAS COLLECTING MY DATA ON 18 OCTOBER 2000.

I THANK HIM WITH ALL MY HEART FOR THE GUIDANCE, SUPPORT AND LOVE

THAT HE SHOWED ME.

I WILL ALWAYS CHERISH THAT.

"Whatever you do, work at it with all your heart, as working for the Lord, not for men."

(Colossians 3:23)

ACKNOWLEDGEMENTS

Firstly I would like to thank **GOD** Almighty for giving me the health and strength to go though with this research.

Without the following people this research would not have materialized. My sincere thanks and appreciation are due to the following people:

- The participants for their co-operation and spending their precious time in the interview.
- My supervisors, Mrs M. Faure and Ms S. Irwin–Caruthers, for their patience, dedication and input. Thank you for your consideration, particularly during the final stage when my car was out of order.
- A million thanks to Prof. L. C.Simbayi for assisting me with the analysis. I really appreciate your patience with my outstanding computer illiteracy.
- Mr W. de Langeni for spending hours assisting me with the computer work.
- My gratitude to the Irish Consulate Lesotho and the University of Stellenbosch for making it possible for me to complete my studies.
- Thanks are also due to Dr C.M. Thompson for providing me with materials; Prof. C. Molteno; Prof. R. Mpofu and Dr C. Adnam for their readiness to help.
- A note of thanks to all my friends for their support, especially Ester Keats Katunga for standing with me when days were dark.
- Lastly, and especially, to my family for believing in me even when it seemed that I was reaching for the impossible. Thuto, thanks for your chain of telephone call and words of encouragement. Sanu, thanks for being on my side up to the last moment, but mostly for giving up everything for me and for your lovely pasta dishes.

TABLE OF CONTENTS

Pages

LIST OF FIGURES

LIST OF TABLES

LIST OF ABREVIATIONS

CBR	Community Based Rehabilitation
DAA	Disability Awareness in Action
IBC	Institution Based Rehabilitation
ICIDH	International Classification of Impairment, Disability and Handicap
KAB	Knowledge, Attitude and Beliefs
PHC	Primary Health Care
NGO	Non Governmental Organization
RDP	Reconstruction and Development Plan
SACLA	South African Christian Leadership Assembly
SPSS	Statistical Package for Social Sciences
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

This chapter presents a short description of the population, the geography, the history and the Health system of South Africa and its restructuring. I will also briefly discuss the participation of the Government and NGOs, the role of health professionals and community involvement in the rehabilitation of people with disability. The research question, the aim and the objectives of the study, as well as the rationale for the study will also be presented in this chapter. Lastly, the terms used will be listed and defined.

A note of explanation:

The Population Registration Repeal Act 114 of 1991 forbids the use of racial classification, however the nature of the research question and the geography of the research setting in this study, require the author to refer to the racial classification of the South African Population Registration Act 30 of the 1950 (Juta's Status of South Africa 1997) in order to highlight the disparity of different cultural beliefs toward disability and people with disability.

1.2 BACKGROUND OF THE STUDY

Insensitivity and lack of awareness of the role of culture can make rehabilitation difficult, particularly in multicultural, multiracial and multilingual societies. Communities from different cultural backgrounds have different beliefs and attitudes towards disability. These differences can have an effect on the outcome of rehabilitation. There is often misunderstanding between health care professionals and clients when it comes to rehabilitation intervention because the clients do not define and perceive disability in the same manner as the health care professionals. Their concerns are not necessarily identical, their solutions are not always the same

and ethnic minority groups may present alternative ways of addressing needs that merit our careful attention (Groce, 1990).

No cultural heritage can wholly explain how any given individual will think and act, but it can help health care professionals anticipate and understand how and why families make certain decisions (Groce & Zola, 1993). Cultural beliefs, practices and attitudes towards illness and disability differ; therefore, programmes and services must be able to accommodate these beliefs, attitudes, and behaviours (McPherson, 1993). McPherson also states that the commitment to serve families of diverse cultural backgrounds must occur at the level of policy, administration, practice and advocacy in order to be effective. Miles (1995) says that in order to devise suitable resources one should first study people's cultures and their concepts of disability.

1.2.1 THE HISTORY OF SOUTH AFRICAN CULTURES

South Africa has a population of approximately 43.8 million with a high population growth of approximately 2.6% per a year (Slabbert, 1992). Formerly the country was populated by indigenous people who were later joined by other cultures from Europe Asia and other parts of Africa. Before the Suez Canal was constructed, the Indian and Atlantic Oceans were used as main shipping routes from Europe to India. This made the immigration of Western populations to South Africa easy. The fertility of the country attracted voyagers to stop over for fresh food and water, while some of the immigrants from Europe and Asia came here hoping to better their living conditions and the flow of immigrants from Europe was encouraged and promoted. The mining and farming industries contributed to the immigration of people from other southern African countries, namely Botswana, Lesotho, Malawi, Namibia Swaziland, Mozambique, Zambia and Zimbabwe as people came here as labourers. Long contracts meant that some decided to bring their families along with them and ended up residing permanently in South Africa. As a result of this considerable immigration, South Africa became a multicultural, multiracial and multilingual nation.

1.2.2 THE SOUTH AFRICAN HEALTH SYSTEM

The main theme of the World Health Organisation (WHO) Alma-Ata conference held

in 1992 was “Health for all by the year 2000". This provided the motivation for all countries worldwide to improve their health services in an attempt to meet that goal. South Africa, like other countries, is striving towards promoting the Primary Health Care (PHC) and community development to meet the demand for an integrated and community based approach to health care.

In 1986, the South African Government formulated the National Health Plan based on the Alma-Ata principles. The plan was initially to be implemented through partnership between the state and the private sector (Dennill, King, Lock & Swanepoel, 1995). The South African National Health Service Delivery Plan was described in 1991 as an intention to provide and develop affordable, accessible, community-oriented and participatory PHC. It was noted in the Reconstruction and Development Plan (RDP) of 1994 that the health policies of the new South African Government required the adoption of the PHC approach in order to meet the needs of the whole population appropriately. Despite the attempts of Government to pursue some of the goals of the plan, Dennill et al. (1995) suggest that the lack of available information and proper identification of needs, especially in the peripheral rural and deep rural areas, has resulted in inefficient planning of the health services.

As part of the promotion of PHC, community-based education and rehabilitation are being introduced as measures to reduce disability (Thorbun & Marfo 1990). Increasing de-institutionalisation has shifted the care of disabled people to their families, which means that community-based care has emerged as the cornerstone of health care.

Home and community care are deeply rooted in the United States and other counties (Stricklin, 1997). The community based-rehabilitation programmes of WHO member countries are achieving better results than programmes in non-member countries and the new member countries. However in South Africa community and home care are only now beginning to develop. More importantly, physiotherapy education programmes are also now introducing community rehabilitation in their curriculum. The creation of posts for community rehabilitation is being proposed as

an integral aspect of affordable, accessible, community-oriented and participatory PHC. Rehabilitation education implementation is a door to community-based rehabilitation. It offers the potential for attitudinal and social change leading to greater opportunity for all (Gregory, 1998).

1.2.3 THE BARRIERS TO COMMUNITY-BASED REHABILITATION (CBR)

The difficulties of initiating community-based rehabilitation education programmes in multicultural nations are noted by Gregory (1998). He mentions that different cultural perspectives complicated the implementation of such programmes, based on evidence from New Zealand, with a unique culture, history, and setting all playing a role. He also observed that philosophical complexities, such as following the traditional restoration models of rehabilitation versus seeking optimal development, were enriched by cultural issues.

Understanding people's culture and its roots is essential and culture must be approached from a people-centred perspective. In health matters where individual and family action is undertaken to bring about recovery, advice is sought from members of the family or community (Kleinman, Eisenberg & Good, 1978). This must be taken into account particularly in issues relating to rehabilitation, a view that is clearly stated in Banja's (1996) definition of culture.

> I define culture as an array or collection of beliefs, habits, and practises that basically serve three functions. First, they determine our social relationships, such as the way professionals relate to their clients; the nature of gender relationships; and family, vocational, and community relationships. Second, they assist individuals to explain life or reality. In medicine this is very important because significant dimension of life and reality is one's health, illness and disability. (1996:279).

This suggests that it is best to give the cultural context consideration during rehabilitation intervention in communities, particularly those of multicultural, multiracial, and multilingual societies like South Africa.

1.2.4 MANPOWER AND REHABILITATION

"No country has a manpower production and distribution pattern that conforms to actual community health needs whether such distribution is by geographical area, by occupation, by speciality, by level of care or by the type of health care setting". (Mejia, 1987)

This also holds true for South Africa where approximately 75 per cent of the population are dependent on the government for their health care (Slabbert, 1992) and where the population growth rate far outpaces the growth in the number of health care professionals.

Data from various sources however, indicates that there ought not to be a shortage of medical practitioners in South Africa (Benade, 1992). Slabbert (1992) mentions that South Africa has the manpower to develop an acceptable health service although certain problems need to be addressed quickly, such as (i) the geographic mal-distribution; (ii) inappropriate training; and (iii) inappropriate utilisation of the different categories of manpower.

The three imbalances mentioned above by Slabbert (1992) are indicators of limitation or complete failure to communicate concepts encompassing disability. Failure to address these imbalances will have serious implications for devising suitable resources acceptable to people's culture and their concept of disability. However, the option of compulsory community service for doctors has been identified as one element of a strategy to rectify the urban/rural mal-distribution of health professionals (National committee on Academic Health Services Complexes, 1994, The South African Medical and Dental Council, 1995).

There are currently eight physiotherapy programmes in South Africa that can only produce approximately 250 therapists per year for a population of approximately 40 million people (Kolobe, 1995). The shortage of therapists is emphasised by Slabbert (1992) who notes that there are not sufficient physiotherapists and occupational therapists to make their services available to all the people of the country. Here too

the geographical mal-distribution must be addressed. The production of therapists is particularly inadequate when compared to the population growth of the country and the number of the people with physical disability.

In addition to there not being enough therapists, there is currently more emphasis placed on institution-based rehabilitation IBC than community-based rehabilitation (CBR). This means that rehabilitation services are accessible to advantaged and urban communities who are able to pay for the services and who can easily get to the areas where services are rendered but not as accessible to less advantaged communities. Rural communities have to travel long distances for such services and, most of the time, they are also unable to pay for them.

IBC is inappropriate model for the developing countries. It serves only a few people (2-3% of the total population) but is irrelevant to the majority of people with disability (WHO, 1982). It is therefore necessary to involve families and community in addition to increasing the number of trained professionals responsible for the rehabilitation of disabled people in their own communities and cultures. According to the figures available, eighty percent of people with disabilities could be significantly helped by existing resources within the community. However, to improve and upgrade community rehabilitation the knowledge of culture, beliefs, values and habits of the community that is being served will be the key to a successful community based rehabilitation. According to Banja (1996) the above mentioned determines the social relationship, such as a professional and client relationships. Therefore, knowing and understanding the culture, beliefs, values and practises of the community that one serves can lead to a more effective rehabilitation outcome.

1.2.4 COMMUNITY BASED PROGRAMMES PARTNERSHIP

South Africa benefits from donations from several countries and international organisational institutions (Health Annual Report 1999), which has helped the country to achieve some of its goals. The Health Annual Report (1999) also reports that 1998 was characterised by a steady process of reconstruction and development, and that substantial changes in the health delivery system have been

achieved. Improved access and appropriate, high quality health services to all South Africans include the following:

- Strengthening primary health care institutional framework through the development of the health system.
- Primary school nutrition programme reaching over 5 million
- Free health care for pregnant women and children under six, which helps improve the health status of women and children.

The report states that there is room for improvement in many other areas. As far as the issue of disability is concerned, the intention is to train health personnel, who would be responsible for the training of community workers and promote home-community based rehabilitation so that people with disabilities could be treated and rehabilitated within their communities. The training will address the imbalance of the geographical mal-distribution of professionals and the inappropriate utilisation of the different categories of manpower observed by Slabbert (1992).

During the ad hoc WHO meeting after the second European Conference on research in rehabilitation, one of the recommendations was that the person with the primary responsibility for community rehabilitation is likely to be the general practitioner or member of the multi-professional team linked to the primary health care service (WHO, 1985). Therefore, the training of professionals is foundational in reaching the goals of community rehabilitation and increased interaction with different cultural groups. At present, the Irish Government is funding the training of health personnel in different dimensions of health in the province of the Free State (Health Annual Report, 1999). There are also numerous small projects throughout the country handling home-community based rehabilitation in the Western Cape area funded by international organisations, such the Kellogg Foundation, WHO, and the others. The South African Christian Leadership Association (SACLA) is one of the non-governmental organisations funded by the international bodies. It helps to train local mothers of disabled children, elected by the community, disabled people and parents of disabled children, with the support of the therapists. The mothers are

trained to provide support and assistance to disabled people and their families, training them in activities and exercises which can prevent disability from getting worse, as well as linking them with health and welfare institutions to obtain aid and appliances. This is in line with the adoption of PHC by South Africa as the strategy most appropriate to meet curative, preventive, promotional and rehabilitative health needs. South Africa has also adopted PHC as a solution to addressing its inadequate health service provision (Hale & Wallner, 1997).

According to O'Toole (1988), the prevention or the reduction of disability though community based rehabilitation is a logical extension of primary health care. Simeonsson (1991) observed that a growing appreciation of the centrality of the family in the development and adaptation of the developmentally disabled is vital. This concept applies in the developed as well as developing countries. Thorbun and Marfo (1990) stated that community based rehabilitation thus seeks to reduce childhood disability in the developing countries by providing intervention to families though the local health system. It was also suggested that the aim of offering rehabilitation services serving all the disabled children countrywide can more practically be met through CBR programmes. In fact the training of the CBR workers to assist the health professionals in providing services for large population (as in the concept of Health For All) has proved to be effective in many developing countries throughout the world (O'Toole, 1991). South Africa is striving to meet this WHO target and is utilising donations from several countries and international institutions (Health Annual Report, 1999) to this end.

Stricklin (1997) notes that both public and private organisations worldwide have provided formal in-home services for more than a century. As the culture, as well as beliefs, values and practises of the community being served determine the social relationships in relation to their attitudes towards disability, such as the client/community and professional relationships, it is important to have some knowledge of these. Such knowledge may mean that the rehabilitation/intervention approach is more readily acceptable.

1.3 THE PROBLEM STATEMENT

Insensitivity and lack of awareness of culture can hinder the outcome of the rehabilitation of disabled people in a multicultural, multiracial and multilingual society. There is often misunderstanding between the professionals and clients when it comes to rehabilitation intervention because their points of view on disability and the solutions proposed differ (Groce, 1987, 1990). Their beliefs, values and practices also differ according to their cultures.

1.4 RESEARCH QUESTIONS

1. What are the beliefs, attitudes and knowledge of the caregivers of physically disabled children in different cultural groups towards disability?
2. How do these beliefs, attitudes and knowledge influence the rehabilitation process?

1.5 AIM OF THE STUDY

The main aim of this study is to identify the beliefs, attitudes and knowledge of the caregivers of physically disabled children in three cultural groups of the Western Cape of South Africa towards disability, and the possible influence of beliefs, attitudes and knowledge on the rehabilitation process.

1.6 OBJECTIVES

1. To identify the knowledge, beliefs and attitude of the caregivers of physically disabled children of different cultural groups.
2. To identify the commonalities and differences in the knowledge, attitudes and beliefs of the caregivers of physically disabled children of three different cultural groups towards disability.
3. To determine the influence of cultural differences on the rehabilitation process.

1.7 THE SIGNIFICANCE AND RATIONALE FOR THE STUDY

It is imperative that health care professionals know the beliefs, knowledge, values, attitude and culture of the client. This study will provide information that will contribute to an understanding of why the caregivers have certain attitudes and why they might take certain decisions relating to the rehabilitation process of disabled children. The information will also assist in the provision of resources that are acceptable to people's culture and their concept of disability.

1.8 DEFINITIONS OF TERMS USED IN THE STUDY

- **Disability** - is any restriction or lack (resulting from impairment) of ability to perform an activity in a manner or within the range considered normal for a human being.
- **Impairment** - is any loss or abnormality of psychological, physiological or anatomical structure or function.
- **Handicap** - is a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a normal role (for the particular age, sex, and social and cultural factors).
- **Caregiver** - any biological relative of the disabled child who lives with the disabled child and responsible for care giving.
- **Community** - a group or a sub-group of people living in a defined area linked by commonalities such as culture, values, habits, religion, language, status, lifestyle and many other factors.

1.9 OVERVIEW OF THE CHAPTER

This chapter presented the background of the research topic, illustrating that there is misunderstanding between the health professionals and their clients when it comes to decision making on intervention or the rehabilitation of individuals with disability due to differences in their perception and understanding of disability. It also relates how South Africa became a multicultural, multiracial and multilingual ("rainbow") nation, how the South African health system works, how PHC was planned, the problem of the uneven geographical distribution of its manpower and the inappropriate utilisation of the different categories of manpower. The community based programme and partnership with the NGOs and the international bodies were also mentioned. Finally the problem statement, research question, main aim of the study, objectives, significance and rationale of the study were discussed, as well as the definition of terms used in the study.

****

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION.

In this chapter I will define disability and its causes with reference to current literature on the subject. In particular I will discuss cultural belief systems, cultural beliefs, positive and negative attitudes towards disability, disability and stigmatisation and the impact of culture, attitudes and stigma on the families of disabled people and disabled people. Lastly I will discuss rehabilitation and how cultural beliefs can affect rehabilitation.

2.2 DISABILITY PERSPECTIVE

2.2.1 Definitions of disability

Definitions are always fascinating, not only for their intrinsic value in a daily use, but also for gaining insight into the nature of the 'powers-that-be' who make and then use definitions (Gregory, 1997). The politics of definitions, particularly when it comes to disability, depend on who is defining it and in which context he is defining it. The perspective of disability between the clients and professionals differ in many ways. The people outside the world of disability have their own way and terms of defining it, while those within that world also have theirs. Gregory (1997) says that definitions and the act of defining can be political statements. He also adds that an often-ignored area in the battleground on definitions concerns who is and who is not included in the disability category.

The pending revision of the International classification of impairments, disabilities and handicaps (ICIDH) provides an opportune time to review the understanding of the consequences of diseases or injuries. This review reinforces the case, made some 20 years ago, that debate is compromised if different meanings are ascribed to the same term (Tennant, 1997). Tennant notes that it was this problem that gave initial impetus to the ICIDH and that the absence of early and clear definitions of impairment and disability in the review disadvantage the readers. The WHO (1980) uses the following definitions:

disability - "any restriction or lack (resulting from impairment) of the ability to perform an activity in a manner or within the range considered normal for a human being"; *impairment* - "any loss or abnormality of psychological, physiological or anatomical structure or function" and
handicap - "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors)".

The WHO definition clarifies some cultural notions of the impairment component. Marks (1997) states that the ICIDH model acknowledges that the level of handicap depends on the cultural norms. The cultural factors and environment may determine the degree of disability. The cultural and environmental aspects are explained clearly by Werner (1988). Werner asserts:

> A child who is mentally slow but physically strong, in a village may not be very handicapped, but in a city or a school may be very handicapped. A child who is physically disabled but intelligent, in a village may be very handicapped, but in a city or school may not be especially handicapped.

Because the WHO definition of disability is based more on the biomedical model most professionals and experts often ignore the cultural factors when it comes to treatment and rehabilitation. This model explains diseases in terms of purely physical parameters, encompassing the notion that diseases are caused by specific pathogens (Brannon & Feist, 1992). The medical and the rehabilitation professionals and medical practitioners tend to conceive of disability as an individual physiological condition requiring the afflicted individual to be given an appropriate medical and/ or rehabilitative support (Imrie, 1997). In one way or the other culture has an influence on the criteria by which disability is perceived, decided and handled. The way one experiences or copes with disability depends on the definition related to disability. Johnston (1977) notes that the notion of health is significantly linked to the way in which people construct reality, something that is often dictated by culturally defined belief systems and expectations, while McCubbin et al (1993) observe that this

construction of reality yields different outcomes that from a traditional provider may appear to defy "reasonable" health or treatment resolutions. If resolutions could use definitions as their starting point it might be easier to achieve acceptable rehabilitation and a good rehabilitation outcome in communities across different cultures, in communities like those of South Africa.

2.2.2 Statistical view of disability

There are about 140 million disabled children in the world (Disability Awareness in Action, 1997). The World Health Organisation estimates that 10% of the world's population is disabled (Ministry in the office of the President, 1995). However, Werner (1988) reports that only two to three per cent of the population is considered disabled by the community. This inconsistency suggests that individuals judge disability according to different criteria from those used by people who undertake epidemiological studies. It is important to realise that few reliable statistics exist for the prevalence of and nature of disability in South Africa. However, the Department of Health in 1995 estimated that the number of disabled people in South Africa constituted 12.8% of the population (Ministry in the Office of the President, 1995). Erfort (1999) reports that at present more than 64 000 people in the Western Cape alone are disabled.

2.3 CAUSES AND PREDISPOSING CAUSES OF DISABILITY

2.3.1 What causes disability?

The above statistics reflect disability resulting from many different causes. Johnston (1996) says disability may arise from genetic disorders, birth injuries, as a result of accidents, following a stroke or due to diseases that progress gradually. Bradshow, Dorrington & Sitas (1992) observed that in South Africa infectious diseases are leading causes of death for Black children under 5 years of age, while trauma, poverty related diseases and chronic diseases related to lifestyles all contribute to high levels of adult mortality. This suggests that the majority of the survivors of the above- mentioned conditions may be victims of disabilities as most of them never get back to their normal health (e.g. stroke patients and head injuries).

2.2.3 Predisposing causes of disability

2.2.3.1 Disability and poverty

A poverty stricken population is susceptible to disability and death. This vulnerability is promoted by their poor economic status, lifestyle and their housing conditions. These conditions expose them to illnesses such as meningitis and tuberculosis. The high proportion of illiteracy together with little awareness of basic social services or of health and education measures (Ministry in the office of the President, 1995) result in a delay in seeking assistance from health care services in the early stages of illness, often resulting in complications which can result in permanent disability. In cases where there is an awareness of such services, inadequate service delivery due to a mal-distribution of resources (manpower) or patients' lack of finances may still result in patients not getting help in time. The mal-distribution of manpower is emphasised by Benade (1992) who states that there is no shortage of medical practitioners in South Africa; but rather that the perceived shortage is relative in nature and due to an uneven geographical and functional distribution.

2.2.3.2 Disability, violence and crime

Among the factors responsible for the rising numbers of disabled persons in South Africa are violence, crime and major shifts to areas of dense population (Ministry in the office of the President, 1995). In both the less developed and the industrialised countries high figures of death from unnatural causes are good indicators of socio-economic disparity between urban dwellers. At present, South Africa is faced with a constant flow of illegal immigrants and other people from rural areas to urban areas resulting in an increased number of squatter camps, which promotes crime and violence. For example, Friedman and Gool (1999) report that about 80,000 people live in Manenberg, Cape Town, but that there are only 5,065 housing units in the area (which would mean about 16 people per unit). Consequently, nearly half of the people live in shacks in the backyards of the formal dwellings. Similarly, King (1999) reports: "We are short of housing for about 150,000 families, but we don't have the land, yet we have a daily influx of people".

Lerer (1997) reports that crime is a dominant theme in current discussions on South

Africa and its future, while Bradshaw et al (1992) states that violence and resulting injuries contribute substantially to the burden of health care in South Africa. Lerer (1997) also notes that even the most cursory review of national crime statistics confirms that the vast majority of crimes against both person and property occur in poorer suburbs. In such areas shooting, bomb-blasts, firearm injuries, stab wounds and house breaking are common daily occurences. Injuries and deaths are reported almost daily due to crime and violence. This undoubtedly contributes to the high prevalence of disabilities.

2.2.2.3 Disability and road traffic accidents

Road traffic accidents pose major health risks and economic problems. They account for hundreds of thousands of injuries and many thousands of deaths each year (McCoy,1989). The road traffic accidents continue to exact a heavy toll in terms of loss of life, injury and permanent disability (Tsai, Lee & Hardy 1978 in McCoy et al,1989). According to Donald (1994), road traffic accidents are a sizeable cause of disability. Pedestrian injuries, in particular, place a large demand on emergency and hospital services (McCoy et al., 1989). This suggests that road traffic accidents are a major contributing factor to disability statistics.

2.4 CULTURAL BELIEFS AND ATTITUDES TOWARDS DISABILITY

2.4.1 Cultural belief system

For the purposes of this study, I will define *culture* as an array or collection of beliefs, habits, and practices that basically serves three functions.

Firstly, culture determines the way we conduct our social relationships, such as the way professionals relate to their clients; the nature of gender relationships; and family, vocational, and community relationships.

Secondly, they assist individuals in interpreting life or reality. In medicine this is very important because a significant dimension of life and reality is one's health, illness

and disability. Cultural beliefs affect how professionals, as well as health-care consumers interpret concepts such as *health*, *illness* and *disability* in a given society

A third function of cultural beliefs and practices is that they serve to differentiate one social group from another social group (Banja, 1996).

Anthropologists generally agree on defining *culture* as the sum total of mores, traditions and beliefs of how we function and this encompasses other products of human works and thoughts specific to members of inter-generational groups, a community, or population (Slaughter-Defoe, Nakagwa, Takanish & Johnson, 1990). An alternative definition of *culture* is something that embodies the interactions among people including the possibilities of variation, for example, by class, region, religion and period which can be attributed to sharing in the tradition of the larger group, whether that group be a nation, tribe, or province (Mead, 1955). On the other hand, Aranda and Knight (1997) define culture as a group's way of life: the beliefs, traditions, values, language symbols and social organisation that become meaningful to the group members. These group members or social groups are differentiated from one another by cultural beliefs and practices (Banja, 1996).

Cultures are determined and maintained through the transmission of value and behaviour from parents to children (Cintas, 1995). Accordingly Knutson et al. (1995), individuals from a common ethnic group typically share cultural practices and pass them on from one generation to another. Membership of the ethnic group provides the cultural identity and lens though which the developing child comes to understand and act upon prescribed values, norms and social behaviour within his or her world (Brookins,1993). This belonging also gives meaning to the child's subjective experiences, and provides a scaffold for interpersonal relationships, behaviours and activities (Gibbs, 1989), as well as a sense of personal survival in the historical continuity of the group (Moore, 1985).

Furthermore, Groce and Zola (1993) observe that ethnic groups also have their own unique and long-standing cultural beliefs, practices and support systems, including

their own definitions of illness. For example, some cultures define diseases in terms of having lost one's soul and are therefore looking for a spiritual healer (Banja, 1996). Some believe illness and disease are the result of a hex or 'the evil eye' (Galanti, 1991). In a setting where one cultural group finds itself where the health professionals are predominantly from another differing cultural system, illness may be approached in what seems to them an oversimplified manner. The prevailing health system may be perceived to be strange or exotic in the way it responds to different physical or mental conditions (Groce & Zola 1993). These authors thus suggest that understanding differing cultural beliefs systems can often provide an important conceptual tool when working with families in culturally diverse societies.

Social justice issues arise from social practices, beliefs, attitudes and policies that affect an individual's basic sense of worth and dignity. These in turn affect attitudes to fundamental entitlements to social goods and services (Banja, 1996). To avoid social justice problems that occur when unjust practices exist or practices that violate personal dignity (Banja, 1996) it is important to have an understanding of the cultural beliefs and attitudes that determine behaviours, guide decisions, and effect interactions with the society (Groce & Zola, 1993). He also says cultural belief systems are a social fact that helps to shape the decisions made by individuals with a disability or chronic illness and their families.

2.4.2 Beliefs

Our beliefs and values constitute our attitude that may in turn affect our behaviour (French, 1994). The relationship between belief, attitude and behaviour is simplified below (Fishbein & Ajken,1975).

Beliefs ⇒

Attitudes ⇒ intention ⇒ Behaviour

Values ⇒

Our beliefs may or may not be correct (French, 1994). Communities, families and individuals have different beliefs, which is why our attitude and behaviour towards

disability also differ. French (1994) notes that the more important or central our beliefs and values, the more resistant they are to change.

McCubbin et al. (1993) says that the family has always been implicitly and explicitly recognised as a critical social unit mediating beliefs and tradition from one generation to the other. Similarly Knutson et al. (1995) note that typically, individuals from a common ethnic group share cultural practices and pass them from one generation to another. Beliefs are rooted within culture and also differ from society to society and are passed from generation to generation within that culture. Some societies, communities or families may believe that disability is caused by physiological and anatomical changes in the body, some may believe that is due to supernatural powers and witchcraft, or that it is provided by the saints or ancestors while others may believe that it is a gift or curse from God. For example, among the Mexican American many disabilities are viewed as having a supernatural cause (Smart & Smart, 1991). They also believe that if disability occurs, they are singled out by God for the role because of their past kindness to a relative or a neighbour who was disabled (Groce & Zola, 1993).

Clapton (1997) notes that in a culture supported by modern Western medicine, which idealises the idea that the body can be objectified and controlled, those who cannot control their bodies are seen as failures. This brings us back to the idea of Banja (1996) who states that culture influences our beliefs about things such as illness or disability.

On the same issue of culture and beliefs Banja (1996) further says that Western society tends to interpret the causes of disability or illness on a biological level emphasising disorganisation or dysfunction at a cellular or inorganic level, while other cultures explain disease or disability as an imbalance in the forces of hot or cold. Still others explain disease and disability as having lost one's soul, and, therefore, looking for spiritual healer. Groce and Zola (1993) observed that the belief that chronic illness and disability are caused by imbalance of element humours in the body is found in various forms throughout Latin American and South Asia. They

also note that the same belief system places the burden of responsibility for disability on the affected individual.

Disability has been seen as a result of evil spirits, devil, witchcraft or God's displeasure, indicative of spiritual or supernatural causes (Higgins, 1992). In the ethnic groups of Southern Africa there are some cultures that believe that disability is caused by witchcraft or is sent by the ancestors if one has failed to follow the traditional rituals. For example, among the Tswana, there is a belief that if a member of the family was not given respect when alive, the person will die with that sorrow and the ancestor's sorrow (*badimo*) may cause disability (which may be temporary) to the members of the family. The Tswana also believe that various types of protection against witchcraft can be sought from traditional healers. They also believe that the healers have the power to return the witchcraft to the witch. The study done by Ingstad in 1998 revealed that although the majority of Tswana people would prefer to use modern health facilities, the belief in the folk healers is very strong and pervasive. Those who turn to folk healers as a first choice often say that they saw no other means of treatment for their problems.

In the Sotho culture, when a woman is pregnant with her first baby the in-laws slaughter a sheep and the pregnant woman has to wear the skin of that sheep throughout the pregnancy. If the woman delivers a disabled child they believe that those rituals were not followed, or if they were followed, they were not followed properly, so the ancestors (*balimo*) were annoyed and gave the woman a disabled child. Within the same culture there is a belief that if a pregnant woman has seen and laughed at a disabled person the ancestors will curse her by giving her a disabled child. They also blame intermarriage of relatives as a source of disability. The latter is also common among American ethnic groups. Groce and Zola (1993) note that this belief is common among Western and Southern Europeans as well.

Ngubane (1977) indicated that among the Zulu disability is believed to be caused by the anger of the ancestors (*amadlozi*) towards their descendents who failed to perform certain traditional rituals. As a result the ancestors have withdrawn their

protection and the descendents then become vulnerable to illnesses and misfortunes. Her study also found that mental illness (*ufufunyane*) is believed to occur as a result of being possessed by spirits – ancestors. The remedy for these misfortunes is to ensure that the necessary rituals are performed (Ngubane, 1977).

In the study done by Jackson and Mupedziswa in Zimbabwe in 1988, the results showed that disability was blamed on witchcraft, God, natural causes and ancestral spirits. Their results revealed that there was likelihood in both non-Christian and Christian groups to ascribe disability to ancestral spirits and witchcraft. Accordingly, another study done by Drews, Foster and Chituna in 1996 in the Northern Nyanka District in Zimbabwe, showed that the Shona tribe believe the causes of illness to include curses and witchcraft. When an individual falls ill, the family consult a traditional healer to find the source of the illness (usually spiritual powers) and to prescribe the appropriate medicine for the illness.

However, this belief is not only common to the ethnic groups of Southern Africa. Groce & Zola (1993) states that in some other cultures, for example, the descendants of English and Irish settlers in rural South and Yankee New England believe a pregnant woman who sees or thinks of an individual with a disability "marks" her baby with the same impairment. They also believe that even mentioning the name of an individual who is ill or disabled puts one at risk for a similar impairment.

In the United States of America, Meyers (1992) notes that the Hmong community belief that the ancestors protect the family, and if they are offended they can cause illness among the family members. The Hmong community also believe that there are good and evil spirits and these spirits, if offended, can cause illness and disability. This author also points that this community would most often prefer traditional medicine to Western medical services. Accordingly, Locust (1988) observed that the American Indians believe that some illnesses are caused by witchcraft and that breaking cultural or religious taboos has spiritual as well as physical consequences for the offender or the members of the offender's family.

Groce and Zola (1993) further note that in a number of African, Caribbean, and Pacific Basin societies, as well as among many native American tribes, witchcraft is strongly linked to ill health and disability. The same authors assert that it is believed that even close association with such a person may place others at a risk.

2.4.3 Disability and religious beliefs

In still other cultures it is quite acceptable to seek a cure through faith at the shrine of a saint, for example, at the well of Saint Teilo in Wales whooping cough is reported to have been cured by drinking well-water from the skull of the saint (Cusack,1997).

With regards to spirituality and religion, Leavitt (1992) says that disability can be considered a curse from God for the sins of family or individual, or as a result of invasion of an evil spirit. For example, Buhler (1886 in Miles, 1995) observed that some verses in the Laws of Manu (XI, 53) summed up a series of examples in which some disabilities are supposed to be 'fitting' retribution for particular sins, the responsibility for which lies entirely with the individual: "Thus in consequence of a remnant of the guilt of former crimes, are born idiots, dumb, blind, deaf and deformed men, who are (all) despised by virtuous" (p. 440). Among the Hindus disability is portrayed as something fearful, usually also a punishment for misdeeds. This is a concept expressed by people with disability who have inherited charitable and paternalistic models of religion that commonly views people with disability as spiritually incomplete (Selway,1997).

In comparison, on the positive side, some people with disability are considered 'lucky' or 'holy'. They are thought to have 'second sight' or an 'extra sense'. Their presence may give protection against the evil eye (Dasen,1988). In addition, some religions that believe that the disability that one is born with is to be accepted with fortitude, and to try to change it would be rebellious (Miles 1995). Cusack (1997) reports that medieval Christians saw the disabled as being in possession of special gifts bestowed by the grace of God. Kalyanpur (1999) says that to the majority of the Mexican Americans and African Americans a child with disability is considered as a

gift from God. According to Ingstad (1998) this belief is also common among the Botswana people.

2.5 ATTITUDE

2.5.1 What are attitudes?

"Attitudes are enduring mental representations of various features of the social or physical world. They are acquired through experience and exert a directive influence on subsequent behaviour" (Baron & Byrne, 1991, p138).

Allport (1935 in Foster & Nel,1991) defines attitude as "a mental and neural state of readiness, organised though experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related". The definition of attitude comprises the following components: cognitive component which refers to our beliefs about objects or persons to whom the attitude is directed; affective component which refers to our evaluation of the objects or persons to whom the attitude is directed; and behavioural component which may manifest itself as aggression, violence, discrimination or preferential treatment.

The way we perceive and decide disability is affected by our beliefs. French (1994) notes that our beliefs and values constitute our attitudes, which may, in turn, affect our behaviour. Accordingly, Gross (1987) points out that in order to convert a belief into an attitude a value ingredient is needed, while, French (1994) says the beliefs and values turn to underpin our attitude and may influence the way we behave.

Attitudes can either be positive or negative. Sometimes people develop prejudice, which Reber (1985) defines as "pre-judgement or to form a strong attitude without sufficient information". He also further adds that prejudice is a negative attitude towards a particular group of persons based on negative traits assumed to be uniformly displayed by all members of that group. Fitzgerald (1997) argues that disability is constructed by us within a very mechanistic and utilitarian framework. She writes:

> That constructed framework has allowed us to heap all sorts of abuse and

> denials upon people with disability. This is because the way in which we, as a society, collectively construct disability has implications for every aspect of the life of a person with disability: going to school, finding a place to live, making friends, getting a job. The way in which we construct disability also defines and confines the spiritual journey of the person with disability, capturing the spirit, along with the body, within institutional confines" (1997).

This author also says that for people with disability the external values, which are in this case, the social and cultural values, play a disproportionately huge role in shaping self-perception for, as a society, we have developed very clearly defined constructions of disability which seek to define the entire person within a one-dimensional framework.

2.5.2 Positive attitudes

Attitudes towards people with disability have been reviewed by many different researchers. Söder (1990) states that the negative and prejudiced assumption towards disabled people is shared by researchers with different theoretical perspectives and is usually based on quantitative empirical studies. Community attitudes towards people with disabilities are frequently negative, and it is these attitudes that are largely responsible for many of the handicaps disabled people experience (Mitchell, Zhou, Lu & Watts, 1993). Chinnery (1991) notes that even among the caring professions, where one would expect a heightened sensitivity, there is lack of awareness of discrimination and its effect upon disabled people.

In contrast, Longmore (1987) and Humphries and Gordon (1992) say the widespread segregation of, and prejudice against, people with disabilities was not seriously challenged until the civil right movements of the 1960s. Longmore (1987) speculated that the major shift in attitudes occurred in Western societies during the eighteenth century with the emergence of a medical model which no longer viewed disability "as an immutable condition caused by a supernatural agency". Mechanic (cited in Westbrook et al, 1993) links a society's acceptance of scientific medicine

with a reduction in the stigma attached to being disabled. In the survey of the experiences of Americans with disability which was conducted in 1986, it was found that life for people with disability has improved since 1975 (International Centre for the disabled, 1986). Similarly the Australian data indicated that community attitudes have become more accepting (Gething,1986).

Other authors consider that attitudes towards people with disability have deteriorated in modern society (Westbrook, Legge and Pennay,1993). The same authors further state that there is evidence that in developed countries attitudes towards people with disability are becoming less negative. Perhaps, the change will shift even to developing countries especially among the ethnic groups.

A change of attitude is the key to establishing acceptable rehabilitation that is applicable to a given culture or community in a given setting whereby families will participate without feeling discriminated or stigmatised. The attitude of peers, neighbours and the public in general are considered as a major obstacle to accomplishing the integration and normalisation of people with disability (Söder, 1990). To achieve fair integration of people with disability in society it is imperative that society changes its attitude towards disability.

However, there are some authors who belief that a satisfactory change of attitude has not yet been reached. For example, Chinnery (1991) commented that as much as the majority of authors believe that attitudes towards the disabled have improved, there are still some complaints that the way Equal Opportunities statements have been developed and are being maintained (largely by able-bodied people) indicate that this is more window dressing than any real commitment. Chinnery's (1991) opinion is that the absence of input from people with disability almost universally prevents them from being effective at meeting their own stated aims. He further declares that without initial and on-going consultation regarding their construction and development, Equal Opportunities policies are an institutionalisation of interpersonal discrimination and prejudice. However Fine and Asch (1988) argue that people with disabilities should rather seen as active participants in the social

constructionist game, capable of actively promoting alternative definitions of their status and situations. Clapton (1997) also reports that some individuals and groups have benefited from the new legislation, but others groups (for example, those with intellectual disability, mental illness, women, people of colour and people in rural areas) are still somewhat excluded.

2.5.3 Negative attitudes

As mentioned earlier, evidence from case studies suggests that an important factor towards disability is attitude (Legge, 1982). Our attitude is the reflection of our perception towards disability. The way one handles disability is directed by our attitudes. Attitudes play a role in determining responses to specific health condition and treatment (Asbury, 1995), for this reason, the concept of attitudes is important in enhancing the understanding of illness and health behaviours (Schlebusch, 1990B).

Negative attitudes foster low expectations, encourage discriminatory behaviour and marginalise people with disability (Bakheit & Shanmugalingam, 1997). Keir (1970) states that negative attitudes lead to the maladjustment of disabled people. However, Paris (1993) believes that the negative attitudes of health professionals towards disabled people should be examined for the following reasons:

- Negative attitudes may adversely affect the self-image recovery of recently injured disabled people.
- Health professionals may influence the attitude of the general public towards people with disability.
- Negative attitudes may affect the delivery of services to disabled people.
- Negative attitudes may influence funding decisions.
- Negative attitudes may influence the attitudes of health care students, thus perpetuating a negative image of people with disability.

In most cases the function of people with disabilities depends on others like caregivers and professionals, as well as the society in which they live. So their attitudes are very influential in shaping the services for people with disability and also in shaping their life opportunities (French, 1994).

2.6 DISABILITY AND STIGMA

Disability, like one or two other illnesses, is a condition that may lead to ostracism by society. Page (1984) notes that a stigma has tended to be associated with those inferior attributes, commonly regarded as major norm infractions, and thus have varying degrees of blame attached to them. The resultant discourse of disability has tended to blame the victim (Imrie,1997) and regard them as inferior, dependent, and, by implication, of little or no value. Cusack (1997) states that to modern society, disability implies a lack or incompleteness on the part of the person so labelled when judged by the standard of the 'complete' person.

This judgement is brought about via the way we have constructed disability. Fizgerald (1997) notes that we have constructed disability within a very mechanistic and utilitarian framework and that constructed framework has allowed us to heap all sorts of abuses and denials upon people with disability. This author further states that the way in which we, as a society, collectively construct disability has implication for every aspect of the life of a person with disability; finding a job, going to school, finding accommodation and making friends. This in turn has an impact on rehabilitation and how disability is by the society. Fitzgerald (1997) further writes:

> There is another dimension to disability, and this is the disability which arises from society's response to the physical condition, to the impairment. It is about the doors which society itself closes on a person with disability - the denial of physical, mental, emotional and spiritual access to our social and moral community. And these doors close because of the way in which we construct disability - our social construction of disability. While our capacity to alter the organic disability may be very limited, our capacity to change the social construction of disability is unlimited.

2.7 STRESS AND THE IMPACT OF CULTURAL ATTITUDES AND STIGMA ON THE FAMILIES OF THE DISABLED

Ethnicity and culture play a significant role in the stress and coping process of care

giving (Aranda & Knight, 1997). The same writers state that ethnicity and culture can also influence the appraisal of stress events, the perception and use of family support and the coping behaviour. According to Birenbaum (1970), in addition to its effect on the disabled individual, stigmatisation may spread to the others in the form of courtesy stigma affecting family members and associates. Similarly, Groce and Zola (1993) observed that there is often enormous social pressure placed not only on the disabled child and adult with disability but also on his or her immediate and extended family.

2.8 REHABILITATION

Primary Health Care is a comprehensive health care that integrates preventive, promotive, curative and rehabilitative care. Rehabilitation is usually opted for after the preventive, promotive and curative measures have failed. Rehabilitation is a process in which those factors which limit a person's effective functioning or behaviour are corrected, modified or adapted to facilitate maximum independence (Beaur,1989). Wade (1996) says that one of the aims of rehabilitation is to reduce handicap, not disability, to a minimal level, and that it is achieved by making the most of the individual's behavioural repertoire, environment and by helping to reduce emotional distress experienced by the patient and his family. The process is usually predominantly conducted in an institution - an environment in which the level of handicap as perceived by the patient and his/her family will be difficult to appreciate. Bauer (1989) says that the nature of the environment in which the person must function is of critical importance in the rehabilitation process.

Bronfenbrenner (1979) describes environment as an active structure of interactions through which the behaviour of a participant in the system is instigated, sustained, and developed, while, Bauer (1989) states that environment is a circle of things, conditions or influences which surround a person, affecting the person's existence or development.

The majority of rehabilitation programmes involve the following three components:

A) regaining of pre-morbid function within the usual environment;

B) adapting function to enable the person to be effective in the usual environment;
C) modifying the environment to facilitate function despite restricted abilities (Kallio,1982)

In order to better cope with disability one needs a familiar environment and culture. For some, culture is a man-made part of the human environment (Herskovits, in Brookins, 1993) including not only artefacts but also laws, myths, and special ways of thinking about social environment (Brookins,1993). A closer look at how this affects rehabilitation follows in the next section.

2.9 CULTURE AND REHABILITATION

The key issue in the rehabilitation process is to remember that the health system and its approach to serving people with disability is not free from the influences of culture. Consequently, there is often misunderstanding between the health professional and clients when it comes to rehabilitation process. This hinders acceptable rehabilitation processes especially in multicultural, multiracial and multilingual nations, like South Africa. As mentioned earlier in this chapter, many ethnic and minority populations, reflecting their own unique and long-standing cultural beliefs, practices and support systems, do not define or address disability and chronic illness in the same manner (Groce,1993) as the professionals in the health sectors. Their concerns are not necessarily identical, and many ethnic and minority groups may present alternative ways of addressing needs that merit our careful attention (Groce,1987 & 1990).

Groce and Zola (1993) argue that to better service children and adults with chronic illness and disability within multicultural societies it is imperative to understand the cultural beliefs and attitudes that determine behaviours, guide decisions and effect interactions with the broader society. The same authors further state that no cultural heritage will wholly explain how any given individual will think and act, but it can help health care professionals anticipate and understand why families make certain decisions.

The way we perceive and handle disability is determined and directed by our cultural beliefs and our attitudes, the same applies to how one approaches the rehabilitation process. Banja (1996) says, "rehabilitation begins in the mind", and that the patient's attitude, motivation and co-operation plays a key role in the rehabilitation process. He adds that cultural beliefs cause people to learn 'approved' ways of being ill, influence their attribution of aetiology of illness or disability, and determine what they expect from treatment and their physicians". Expectations also differ according to cultures and societies.

An example of a client's expectations from treatment is clearly reported by Kleinman in the 1975 study in Banja (1996). This example relates a Taiwanese patient's expectations when visiting a doctor. Kleinman (1975) reports:

> The patients responded that, when they see Western doctors, they expect to be provided with injection but not explanation; when they visit Chinese doctors they expect to have herbs prescribed and questions answered; and when they go to folk practitioners, they expect the folk practitioner to be more interested, to spend more time and to be more responsive to their needs (p. 280).

In South Africa the same pattern is found among the Xhosas, Zulus and Sothos. When the client is seeing a traditional healer the client expects the healer to tell her/him the problem, who caused it and to provide the traditional medicine to get rid of the problem. When seen by a Western doctor they expect him to use a stethoscope, give an injection and different types of tablets. Mostly the clients choose to see therapists at the same time as seeing the traditional doctors who they believe will finally get rid of the problem and the source that caused the disability. In some cases, clients see Western doctors and go for rehabilitation simply because they want to benefit from a Government grant or in the hope that their child may be taken to an institution where they will be cared for by employed caregivers.

Groce and Zola (1993) report that there are persistent traditional expectations or beliefs in many societies that more severely disabled children will simply not survive,

and because of this, the parents choose either to neglect such a child or, conversely, to shower them with love and attention because they are expecting them to die very soon. They further argue that such attitudes, unfortunately, may severely compromise attempts to encourage parents to plan realistically for the future of their disabled child. This may also contribute to lack of interest in the long-term rehabilitation process of such a child, as the expectation is death and not survival. More sadly, such attitudes and expectations deprive the child from benefiting from early intervention and utilising the existing health services.

What the person should do when he or she becomes ill or disabled is another product of culture (Banja,1996). Groce and Zola (1993) note that when the traditional belief is that a disability runs in a family or is evidence of divine retribution, a family with siblings of marriageable age are more likely to hide the disabled member to avoid reducing their chances of finding suitable mates for other children. This means denying the disabled member the opportunity of receiving rehabilitation or of appropriate planning for the member's future such as education where possible. Enormous social pressure is thus placed not only on the disabled child and adult, but also on his or her immediate family (Groce & Zola, 1993). The same writers affirm that even when such families are aware of the need for special services, they may be reluctant to participate in the programs, fearing that these will call attention to their members' physical or intellectual limitations.

Hiding the disabled person has long been common among the ethnic groups in Southern Africa. During the reign of Chaka and Moshoeshoe disabled people were regarded as a curse on the entire clan, so that disabled and older persons used to be put at the entrance of the kraal where the oxen could walk over them until they died, or they were hidden so that other people would not know that they existed. It is a sad thing that even today those taken for rehabilitation are sometimes taken more for the sake of getting a grant, and not for the benefit that can be obtained from the rehabilitation programmes as such.

Ignoring patients' cultural backgrounds often results in misinterpretation of their

behaviour (Westbrook et al,1993). In agreement with this, Banja (1996) states that if the patient's beliefs are very culturally entrenched, it is unusual for the professional to convert the patient to accept his/her explanation because when the patient leaves, he or she will revert to his or her beliefs. Banja (1996) adds that patients are often respectful and deferential, and nod their heads affirmatively, and professionals assume consequently that the patient is going to be compliant but that this merely reflects politeness and not agreement. This misunderstanding is an indicator of how important it is to pay attention to the wholeness of the client in regard to her/his culture and beliefs during rehabilitation.

Miles (1995) stresses that to devise suitable resources one should study people's culture and their concepts of disability. Similarly Groce and Zola (1993) state that at a broader level it is clearly impossible to understand chronic illness and disabilities in a multicultural society without more fully understanding some of the basic and long-identified issues in a cross-cultural communication and immigrant and minority experience.

Having thus stressed the role cultural understanding plays when treating people from various backgrounds, it should also be borne in mind that people are unique people and that people who share several cultural components may not share the same values and beliefs (Dillard et al.,1992). Thus for all the role players in the rehabilitation of the disabled all the above mentioned factors must be considered when making a decision about their rehabilitation.

2.10 OVERVIEW OF THE CHAPTER

In this chapter I reviewed some of the different perspectives on disability, the causes and the predisposing causes of disability. Published concepts of cultural beliefs and attitudes towards disability were reviewed, together with the effect of stigmatization of the disabled and their families and the implications this has for rehabilitating the disabled.

****

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

The methodology will be discussed in terms of the research design, selection of the research areas, sampling and the method of data collection and data analysis.

3.2 RESEARCH DESIGN

My initial approach to the study was predominantly qualitative. This method was chosen for the current study because it is a method that is rich, full and holistic (Miles, 1979). It can preserve the chronological flow, assess causality, help to derive a fruitful explanation, and most importantly, is likely to lead to "serendipitous findings and new theoretical integrations" (Miles & Huberman,1994). This research method also values the participants' perspectives on their world and seeks to uncover those perspectives; it views inquiry as an interactive process between the researcher and the participants. The method is primarily descriptive and relies on what people say as the primary data (Marshall & Rossman,1989).

However, I later decided to adopt a method of methodological triangulation, which is defined by Leedy (1993) as a compatible procedure designed to reconcile the two methodologies (quantitative and qualitative) by using elements from each of the major methodologies for the purpose of understanding the research problem deeply. Triangulation was used to maintain the validity of findings and to avoid any possible limitations of the research method (Babbie,1992), as well as to overcome any weaknesses of individual methods (Brewer & Hunter, 1989). Another important advantage of triangulation is that it tends to break down divisions between research perspectives, for example, 'experiment' and 'naturalistic' or 'quantitative' and 'qualitative' researches. In this manner it may assist in removing prejudices concerning the relative value of various research methods (French, 1993).

Since the study remained predominantly qualitative, it includes more use of open-ended questions via the structured interview in which, according to French (1993), the interviewer goes through the questions verbally with each respondent. This method allows the interviewer to get the respondent's experience, feelings, opinion, knowledge and practices within the context of disability among the different cultural groups.

The personal and social meanings that people use to structure or construct their lives in the form of cultural and belief systems cannot merely be treated as statistical variables, but need to be explored more deeply. This could be achieved by means of triangulation, that is by combining two research methodologies, which in this study are quantitative and qualitative methods. Cuba and Lincoln (1985) state that triangulation of methods is the best means of ensuring that one will be able to make sense of data collection through interviews. According to these authors, the interview should not be thought of as a single-faced approach. They further say that research that is based solely on interviews may be sabotaged or crippled. In support of methodological triangulation Dexter (1970) states:

> Any planning for a study assuming a heavy reliance upon elite interviews should have a contingency plan, an escape hatch, an alternative so that if the elite interviews prove basically uninformative some other technique can be substituted (p. 17).

French (1993) observed that all the research methodologies are equally good. The goodness and the strength of each method, however, depends on what a researcher is investigating. Parry (1991) points out:

> The differences do not necessarily mean that one is superior to the other or that they are in competition with each other. We need only understand that different styles of research reveal different kinds of useful information (p. 437).

French (1993) stipulates that quantitative and qualitative research can be mutually enhancing. She further adds that qualitative research may allow the researcher to give meaning to quantitative data, and quantitative data may help to put qualitative research in the wider context. In accordance with that, I used the two methods for the current study to balance the pitfalls of each method.

A quantitative methodological approach was used in a form of closed questions on the knowledge, attitudes and beliefs of the caregivers of three different cultural groups towards disability. The three groups of preference for the study were Blacks, Coloured and Whites. The quantitative approach was utilised in the form of Knowledge attitude and beliefs (KAB) surveys and the qualitative component was used to gain insight into their knowledge, attitude and beliefs.

3.3 RESEARCH SETTING

The respondents for the study were recruited from the two tertiary children's hospitals of the Cape Metropolitan Area, namely, the Red Cross Children's Hospital and Tygerberg Hospital. These referral hospitals provide services for patients from the following regions: West Coast and Wineland, Metropole, Boland and Overberg; and Southern Karoo. These hospitals cater for the different cultural groups living in the above-mentioned areas. This facilitated recruitment from the three main cultural groups of the Western Cape, namely Blacks, Coloureds and Whites. Dillard et al, (1992) says that one's idea and attitude come from a different setting or environment. The researcher hoped that selecting respondents from the referral hospitals that cater for different cultural groups, who come from different settings and environments could help to provide the needed information for this particular study.

3.4 RESEARCH SAMPLING

KAB surveys rely on probability sampling to ensure that the results are

representative of the population of interest in the study (Katzenellenbogen et al., (1997). According to Denzin (1970), the researcher does not necessarily have to rely on one sampling method. Denzin (1970) points out:

> Sampling does not end until a completely grounded theory is constructed…. The logic of ongoing inclusion suggests that triangulation sampling procedures should be utilised. Rather than restricting observations on one data source, the investigator must attempt to locate as many data as possible, thus increasing the probability that his theory will be fully tested (p. 83).

In this particular study, triangulation sampling was adopted. Both probability and non-probability sampling were utilised. Firstly, under probability sampling systematic (quasi-random) sampling was adopted. Every third caregiver who came to the Physiotherapy Department for the service of the child with disability was picked for the study.

Katzenellenbogen et al. (1997) report that it is difficult to ensure that translated questionnaires truly represent the original. He says the translation poses further problems when the target language(s) lack the vocabulary suited to the goals of the questionnaire. Because of this, the component of a non-probability sampling, purposive (judgemental) sampling was utilised. The researcher only interviewed the respondents who could understand English and speak it well enough to participate in the study.

Secondly, the method was used because of the limited time and funds to train research assistants who could interview and translate the questionnaire into the respondents' own languages, that is, Afrikaans and Xhosa. According to Katzenellenbogen et al. (1997) when translating a questionnaire, to evaluate comparability, it may be necessary to back-translate the new questionnaire into the original language, which may need bilingual people to do so. Due to the already mentioned reason purposive sampling was thus deemed more appropriate for sampling triangulation for the current study.

3.5 RESEARCH SUBJECTS (SAMPLE)

3.5.1 Selection of the respondents

As the family has always been implicitly and explicitly recognised as a critical social unit mediating cultural beliefs and tradition from one generation to another (McCubbin et al, 1993), the study focused on the biological caregivers of the disabled children. To identify the beliefs of different cultural groups towards disability and to document their influence on rehabilitation, the biological caregivers could be considered the most reliable source of information since they are usually the decision makers and the closest people to children with disability. For this reason, it has been assumed that the information elicited from them would be informative for the future planning of treatment/rehabilitation intervention for the children with disability.

The sample consisted of 60 biologically related caregivers of physically disabled children from three cultural groups of caregivers, that is: 20 Blacks, 20 Coloureds and 20 Whites.

3.5.2 Criteria for inclusion

The parent/caregiver was interviewed only if the child with disability met the following criteria:

- The disabled child should have a physical disability which prevents her/him from performing at least one activity of daily life, for example personal washing, walking, eating or dressing (i.e. partially dependent) or prevents her/him from performing all activities of the daily living (that is, totally dependent) in the manner or within the range considered normal for a child of her/his age (WHO, 1980).
- The minimum age of the disabled child should be 2 years old because it is assumed that at this age a normal child would have completed the milestones. By this time the caregiver would be aware of the disability of the child. The maximum age of the disabled child should be 13 years because the children's hospitals do not admit patients who are older than 13.

- The child with disability should be living with the family permanently, not in an institution.
- The caregiver should be biologically related to the child with disability, for example, a parent, grandparent, an uncle or an aunt.
- The caregiver should be able to understand written and spoken English, as well as to speak English well enough to participate.

5.3.3 Criteria for exclusion

Prospective participants would not be included if

- The caregiver has a psychiatric problem.
- Or is unable to understand written and spoken English.

3.6 METHOD OF DATA COLLECTION

The method of data collection was by means of a questionnaire-based survey, referred to as a structured interview, whereby the researcher went though the questions verbally with each respondent (French, 1993).

3.6.1 Choosing the research method

To measure the variables of knowledge, attitudes and beliefs of three different cultural groups towards disability the (KAB) questionnaire approach, popular in epidemiological research (Katzenellenbogen et al. (1997), was considered appropriate for the current study. According to Katzenellenbogen et al. (1997), this method can be used to increase understanding of association between social or psychological factors and health problems and to generate support for health programmes by demonstrating existing attitudes and needs. They further say that repeated KAB surveys can assist in identifying the shortcomings as well as the strengths of existing programmes. The KAB approach was used for the quantitative component of the questionnaire.

To gain more insight and to extract additional information needed for the study, the qualitative method using structured interviews was adopted. Open-ended questions

were used in the qualitative part of the survey. Open questions provide a wealth of rich information, as they allow respondents to explain their views and feelings, and to answer in their own words (French, 1993).

3.6.2 Reliability and validity of KAB

KAB surveys have been applied to a wide range of problems, such as, alcohol and tobacco consumption, use of preventive health services, traffic safety and prevention of spread of HIV infection (Katzenellenbogen et al., 1997). However, where they have been specifically examined, their reliability and validity have not been as good as assumed (Okediji,1973, Stone & Campbell, 1984). Although their reliability and validity have not been that good, they remain popular instrument on theories where behaviour is influenced by knowledge as well as attitudes and beliefs, for example, tobacco and alcohol consumption, HIV infection, and so on.

3.6.3 Research instrument

To identify the knowledge attitudes and beliefs and the way in which they might influence an individual's decision when it comes to rehabilitation, the KAB survey in the form of structured interview was a chosen for this particular study. The questionnaire and the interview are both survey methods in which information is gathered about a group of individuals in a systematic way (French, 1993).

The questionnaire consisted of three parts (for more details see the appendix) as follows:

Part I:

- Demographic data of the caregivers of the children with disability.
- Demographic data of the children with disability.

Part II:

The KAB questionnaire

The quantitative component of the questionnaire consisted of the closed ended questions, that is, Question A in every question.

Part III:

This was the qualitative component of the questionnaire. It consisted of open-ended questions to allow the respondents to answer in their own words and to expand on the answer as much as they could. This component consists of Question B of every question of the questionnaire.

3.6.3.1 Questionnaire construction

When designing a questionnaire certain key principles need to be borne in mind. Designing a questionnaire is a skill and does not involve merely jotting down a few questions on a paper (Hicks, 1995). Rather, a questionnaire is a tool for data collection, and is therefore an important research instrument (Oppenheim, 1992). Before the questionnaire can be compiled, its purpose must be specified. It is very important that a questionnaire is only chosen if it provides the best way of answering the particular research question or hypothesis (French, 1993). Bell (1987) states:

> You will only reach the stage of designing a questionnaire after you have done all the preliminary work on planning, consulting and deciding what you need to find out. Only then will you know whether the questionnaire is suitable for the purpose and likely to yield usable data (p. 58).

Hicks (1995) asserts that the design and use of a good questionnaire should follow the following steps:

a) identifying general topics to be covered by the questionnaire that will reflect the objectives the researcher have in mind;
b) initial draft of the questions covering all these topics;
c) piloting the questionnaire;
d) modifying the questionnaire by using the information collected from the pilot trial;
e) carrying out the second pilot study to establish whether the earlier problems have been ironed out or not;
f) and administration of the questionnaire in the actual study.

The above steps were followed in the current study. The questionnaire covered the respondents' knowledge, attitude and beliefs towards disability. The questionnaire was divided into two parts, which are closed ended and open-ended questions. The closed ended questions were utilised for the quantitative methodology component and open ended for the qualitative section. Since the aim of the study was to identify variables on knowledge, attitudes and beliefs the questions on the quantitative component were also divided into three component of the KAB survey. The version by WHO Global Program on AIDS Research Package (1990) was adapted to formulate the question on the three variables.

The questions on knowledge were designed in the way that the response possibilities would be: YES, NO, DO NOT KNOW and NOT SURE. According to French (1993), it is wise to allow the respondents to indicate when they do not know. The researcher gave that option to the respondents by adding DO NOT KNOW and NOT SURE to dichotomous questions.

French (1994) reports that our beliefs and values constitute our attitudes, which may in turn affect our behaviour. It is actually difficult to separate attitudes from beliefs because our behaviour is influence by both our beliefs and attitudes, and the latter is also influenced by our experiences. However, the questions on the attitudes were formulated in such a way that the possible responses were: STRONGLY AGREE, MILDLY AGREE, MILDLY DISAGREE, STRONGLY DISAGREE, and DO NOT KNOW. The same style was applied to the questions on beliefs, but the possible responses were: NOT LIKELY AT ALL, VERY SMALL CHANCE, MODERATE CHANCE, GOOD CHANCE, DO NOT KNOW, NOT SURE or the same set of responses for the questions of attitudes, as some questions would be formulated in that way.

3.6.3.2 Question content

The content of the question determines the response from the respondents. As Bailey (1987) reports, four aspects of question contents are likely to affect

respondents' behaviour:

a) the degree to which the topic arouses anxiety;
b) concern with social desirability;
c) the salience of the topic;
d) and the wording of the question.

Neglecting the above could result in a failure to elicit information from the respondent especially to questions that deal with topics that may be perceived as threatening, sensitive or embarrassing. In such topics one may end up with respondent refusal to participate or a response only to certain questions. Alternatively, the person may simply give a false response, one that they deem to be socially desirable (Schnetler, 1989).

The question content differs according to the type of information the investigator requires. According to Schnetler (1989), a distinction can be made between four basic type of question content:

a) factual question (usually focusing on sociodemographic and personal information);
b) questions on opinions and attitudes (these probe the feelings, convictions, ideas and values regarding a particular issue);
c) information questions (aimed at discovering what respondents know about certain events);
d) and the questions about behaviour (i.e., the presence or absence of the behaviour, the nature of the behaviour, frequency of behaviour, the degree of the behaviour and the degree of importance of behaviour).

Since the core of the study aimed at identifying the knowledge, attitudes and beliefs towards disability and their influence on rehabilitation, behaviour was not covered in the question content. The content predominantly covered the following:

a) Factual questions, both the demographic data of the caregivers and the disabled child were taken. That included age, sex, religion, home language, the highest level of education, the marital status of the parents and so on.
b) Questions on opinions and attitudes, the respondent were asked their opinion

about many issues concerning disabilities and rehabilitation of disabled children. They were also asked about their feelings on employment of disabled people and their freedom in getting married and having children.

c) Information questions, in which the researcher asked respondents on their knowledge about disability and its causes. (For the full questionnaire see Appendix 3.)

3.6.3.3 Question wording

The actual wording of the questions needs care. If it is too complicated, some respondents may be reluctant to continue with the questionnaire, or invalid answers may result from misunderstood questions. In contrast, if the wording is too simple, it may make respondents feel insulted and lose interest. Also, if the question is phrased in an evaluative tone the respondent may not answer honestly. A good example is the closed ended question with yes/no as a response. In this case the respondent may choose a "yes" option thinking or feeling that it is more socially desirable. Hicks (1995) suggests that good question design is indicated by lists of do's and don't (using the do and don'ts in the questions). In the current study this style was applied. The respondents were also given the option of indicating if they did not know the answer. This was applied to avoid dishonesty in the answers.

Clear, self-explanatory and unambiguous questions are the most appropriate tool in question design, especially when working with semi-literate societies. In some cases the researcher may be tempted to use certain slang terms, assuming that the respondent may understand them better. Such terms may be as unfamiliar as formal scientific terms are to some respondents. A general guideline then is to use the most descriptive terms, avoiding the use of both slang and formal/scientific terms (Bailey, 1987).

3.6.3.4 Format of questions

Open-ended and closed questions are the two basic formats used in survey research (Bailey, 1987; French, 1993; Schnetler, 1989).

3.6.3.4.1 Open-ended questions

Open-ended questions provide a wealth of rich information (French, 1993). They allow the respondent to express responses freely, that is, no fixed response categories are contained in the question (Schnetler, 1989). Open-ended questions have an advantage when a variable is relatively unknown or unexplored to the researcher (Fouche, 1998). The same author also says that in such cases, open-ended questions enable the researcher to explore the variable better and to obtain some idea of the spectrum of possible responses.

Schnetler (1989) postulated that open-ended questions may elicit more reliable responses on question which measure sensitive behaviour. They allow more opportunity for creativity or self-expression by the respondent (Bailey, 1987). Open-ended questions similarly do not restrict the respondent's responses, and therefore, are ideal for questions where wide range of possible answers could be elicited (Bailey, 1987; Schnetler, 1989).

As Fouche, 1998 lists the disadvantages of open-ended questions as follows:

- If there are a lot of open-ended questions this may lengthen the time of completion and respondents may be tempted to leave the answers incomplete, which decreases the real value of the data obtained from the questionnaire. (To avoid this the researcher wrote the answers down for the respondents.)
- Including of many open-ended questions makes it more expensive, more time-consuming and more liable to error.
- They also lengthen the time necessary for processing of the data.
- Responding to these questions in a self reporting format requires literacy and writing skills, as well as an ability to express one's opinions and feelings verbally (Bailey, 1987).

3.6.3.4.2 Closed ended questions

Closed ended questions offer the respondent the opportunity of selecting (according to instructions) one or more response choices from a number provided to him

(Fouche in Van Schaik, 1998). The questions are usually fairly simple to answer, and equally easy to code and analyse (Bailey, 1987). The degree, frequency and comprehensiveness of a phenomenon can be ascertained quite meaningfully by means of closed questions (Fouch,1998). He further says closed open-ended questions are advantageous in that the results of investigation can be made available fairly quickly, especially when a substantial amount of information about a subject already exists and the response options are relatively well known. Other advantages of closed questions are that respondents understand the meaning of the question better, questions could be answered in the same framework, and responses can consequently be better compared with one another (Schuerman, 1983).

The disadvantage of the closed ended question is that, if used alone, important information can be missed because it can never completely provide for the full variety of response options that may exist on any particular subject (Fouche, 1998). Other disadvantages are that respondents may simply guess the answer or randomly select one of the options without really thinking about it (Bailey, 1987).

3.6.3.5 Piloting the research instrument

Before the questionnaires are distributed it is very important to test them on few people in order to iron out any remaining problems that may have been overlooked (French, 1993). Similarly, among her thumb rules, Hicks (1995) states that piloting a questionnaire, that is, giving out the questionnaire to a number of people (who do not necessarily come from the population at whom a questionnaire is targeted) in order to collect feedback on unclear or insensitive questions and ambiguous instructions is important. She further postulates that a second pilot trial should take place to establish whether or not the earlier problems have been ironed out. With this in mind, four members of a church who do not have disabled children or belong to population being studied were interviewed. Feedback from this pilot trial led to the addition of the questions on the rights of people with disability, such as, "do you think people with disability should take part in sports?".

The second pilot testing of the questionnaire was given to a group to whom the questionnaire was targeted. It was also administered to four caregivers who had brought children with disability for treatment at Red Cross physiotherapy department but who were not included in the study. After that a few adjustments were made, including allowing more space for the open-ended questions and adding the response, "DON'T KNOW", on the quantitative component of the questionnaire.

3.7 PROCEDURE OF THE MAIN STUDY

To introduce the researcher a letter was sent to the research area i.e. Tygerberg Hospital and Red Cross Children's Hospital (see appendix F). The letters were sent together with a copy of the research proposal to each hospital to give a clear understanding of the research to the superintendents. The heads of the physiotherapy departments were also provided with the same documents, plus a reply letter from the superintendents, which granted the researcher permission to do the study.

Since the method of sampling was systematic, the researcher checked the physiotherapy patients' list of that day. From that list, every third caregiver accompanying a child for treatment was picked, provided that he/she was a biological relative of the disabled child and provided he/she could understand and speak English well enough to respond to questions.

Partridge and Barnitt (1986) believe that research participants should give their informed consent, both verbally and in writing before the research proceeds. French (1993) states that it is only possible to give informed consent if a full explanation of the research is provided such as: a) the aim of the research; b) the purpose of the research; c) the identity of the researchers; d) the nature of the institution where the research will be undertaken; e) how the individual was selected; f) what participation in the research entails; f) and to what use the research will be put. The researcher explained all the above-mentioned factors, except the nature of the institution since the respondents were already in the department at the time of orientation of the research project. The respondents were also assured that they had the right to ask

questions and to opt out of the research at any time if they wished.

Before proceeding with the research questions the respondents were asked if they fully understood what the proposed research was about and if they were willing to participate in the study. All the participants who were willing to do so were interviewed. The brief summary of that verbal explanation of the research project was also given in writing on the front page of the questionnaire for further clarity and understanding and to obtain written consent from the respondent (see Appendix F). The respondents were asked to tick 'yes' if they understood the research project and also if they were willing to participate in the research. Peace (1993) recommends that giving the informed consent can be used as a means of obtaining access to research participants. The researcher also used the exercise to obtain access to the participants as well as to document informed consent.

A respondent may be considered anonymous when the researcher cannot identify a given response with a given respondent (Rubin & Babbie, 1989). To gain their co-operation and to maintain confidentiality, as well as anonymity, the respondents were asked not to give their names to the researcher or to write them on the questionnaire or to write the answers in their own handwriting. The researcher read the questions to the respondents and wrote the responses down.

Anonymity and confidentiality promotes openness and honesty of the respondents, some times even on sensitive and personal information. To stress the importance of anonymity and confidentiality Homan (1991) points that one of the major reason for assuring research participants of anonymity and confidentiality is to secure their co-operation, and it offers the researchers some legal protection (French, 1993). In respect of anonymity and confidentiality French (1993) states that anonymity and confidentiality also extend beyond the written word to include photographs, videos and video recording and raw data. She further adds that coded information should always be kept well away from research data and destroyed when it is no longer in use for the research project. To this end, I undertook to destroy all the raw data immediately after the marking of this thesis.

Due to a shortage of respondents, the researcher had to get additional respondents from the originally planned research area. Caregivers who were seen by Red Cross Children's Hospital doctors at the SACLA Rehabilitation Project and then referred to Red Cross for physiotherapy were included in the study, as well as caregivers who took their disabled children for group therapy at the Marie Botha Centre at Tygerberg. The same procedure was followed as for the physiotherapy departments of the two hospitals.

3.8 METHOD OF DATA ANALYSIS

Qualitative data and the demographic data of both the caregivers and their disabled children were analysed using the computer based Statistical Package for Social Sciences (SPSS). To test the statistical significance of differences between the three variables the Pearson chi-square test of independence, 3x3 table was used.

When analysing the qualitative data, the responses supporting the answers given in the questions A (quantitative data) were constructed into themes and the Pearson chi-square test was used to test the statistical significance differences of the three variables.

3.9 OVERVIEW OF THE CHAPTER

The methodology of the study in terms of research design, section of research setting and sample, method of data collection, analysis and ethical consideration were presented in this chapter. The study utilised methodological triangulation. Because of the nature of the study, sampling triangulation was also utilised. A KAB survey was adapted in the form of structured interviews to identify the knowledge, attitudes and beliefs of the three cultural groups. The version by WHO Global Programme on the AIDS Research package (1990) was adapted to formulate the questions. Both closed- and open-ended questions were included. Finally the main procedure of the study and the method of analysis were presented.

****

CHAPTER FOUR
RESULTS

4.1 INTRODUCTION

This chapter will present the quantitative data from the closed questions and the qualitative data of the open-ended questions from each individual question (for example, Question 4A is a closed question while Question 4B is open-ended). This will be done in order to provide a clearer understanding of the research problem (Leedy, 1993) and to overcome the weakness of individual methods (Brewer & Hunter,1989).

The quantitative data (answers to closed questions, that is, response A for each question) will be interpreted first, followed by the qualitative data (open-ended questions, that is, responses B). The main themes from explanations provided in support of the results from the closed questions will be used as a basis for analysing the qualitative data. Both the frequencies of responses and the themes will be further analysed according to cultural groupings.

When the reliability of the questionnaire was tested using two questions from the questionnaire (Question 34 & Question 35) versus two other questions (Question 10 and Question 17 respectively) the responses were consistent. For this reason the responses from Question 34 and 35 will not be reported on as they were merely cross-check items for Question 10 and 17 respectively (see Appendix F).

PART I

4.2 SOCIO-DEMOGRAPHIC DATA OF THE CAREGIVERS (RESPONDENTS) OF DISABLED CHILDREN

4.2.1 Age

The ages of the respondents are summarised in Figure 1. The figure shows that there was a similar distribution of ages across all three cultural groups. When assessed using a chi-square test, there was no significant difference in the age groups *(p > 0.05)* of the three cultural groups.

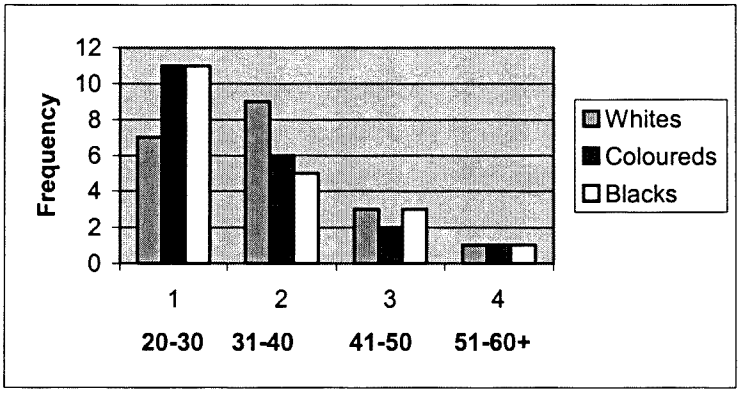

Figure 4.1 Distribution of age (in years) of the caregivers.

4.2.2. Gender

The gender profile of the sample is shown in Figure 4.2. The figure shows that the sample was mostly female in all three cultural groups.

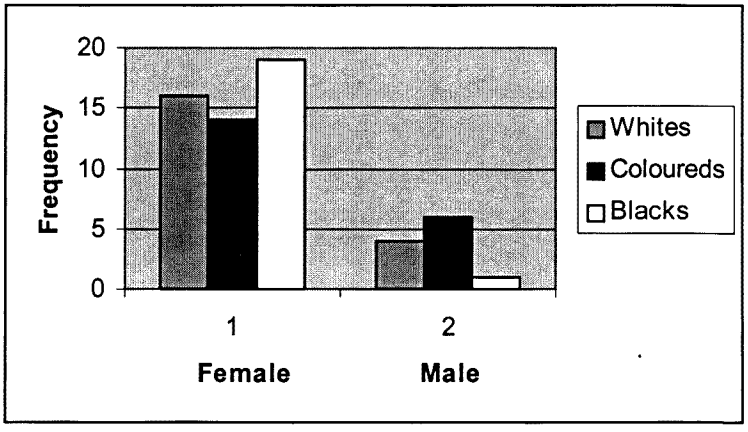

Figure 4.2 Gender profile of the sample.

4.2.3 Home language

In terms of home language, the Whites mostly spoke Afrikaans (n = 13) while a minority of them spoke other languages (n = 7). All the Coloureds spoke Afrikaans, while the Blacks mostly spoke African languages. The most popular language among the Blacks was Xhosa (n = 16).

4.2.4 Religion

The religious affiliations of the sample are shown in Figure 4.3.

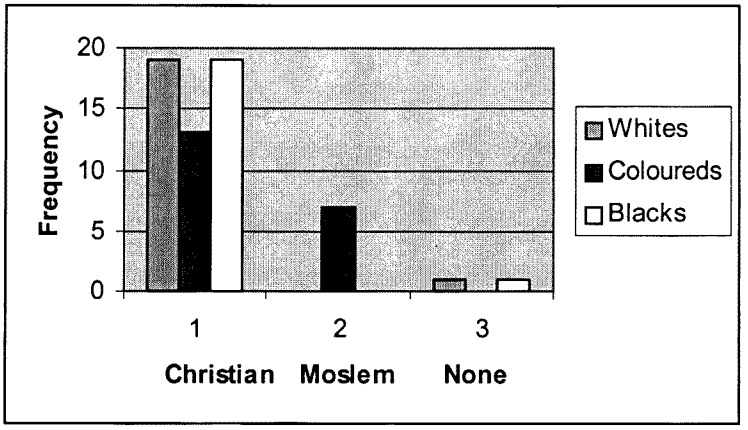

Figure 4.3 Religious affiliations of participants in the present study.

This figure shows that there were similar distributions of religions among the Black and White cultural groups. However, there were some Moslems among the Coloureds. When assessed using the chi-square test, the differences were shown to be significant, Pearson chi-square *(6) = 16.710, p < .01.*

4.2.5 Marital status

Figure 4.4 shows the marital status of the sample. According to this figure, the majority of the parents of disabled children among the Coloureds and Whites are married. When assessed using the chi-squared test, the differences between the cultural groups were significant, Pearson chi-square *(6) = 17.727, p < 0.001.*

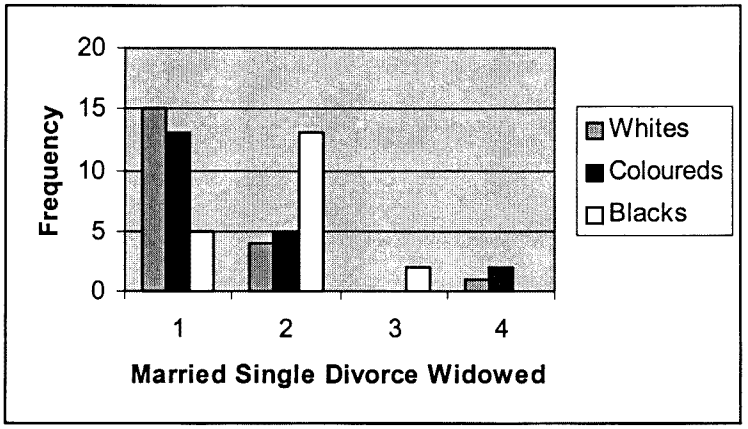

Figure 4.4 Distribution of marital status among the sample.

4.2.6 Number of children parents of disabled children had

The number of children the parents of the disabled children had are shown in Figure 4.5. The figure shows that the parents in all three cultural groups mostly had one or two children only. When using a chi-squared test to assess the differences, they were found not to be significant across the three cultural groups *(p > 0.05).*

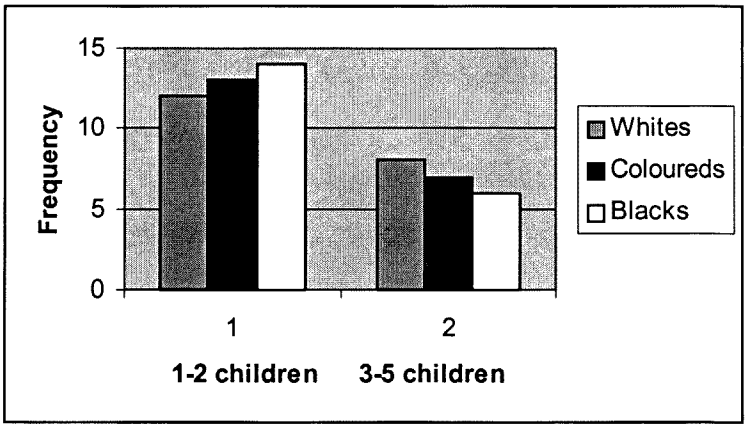

Figure 4.5 The number of children the parents of disabled children had.

4.2.7 Caregivers highest level of education

Figure 4.6 shows the highest educational level attained by the caregivers. The figure shows that the majority of the caregivers in all three cultural groups had attained high school education. There was no respondent who had no education in all the three cultural groups. When assessed using a chi-square test, the differences were not significant *($p > 0.05$)*.

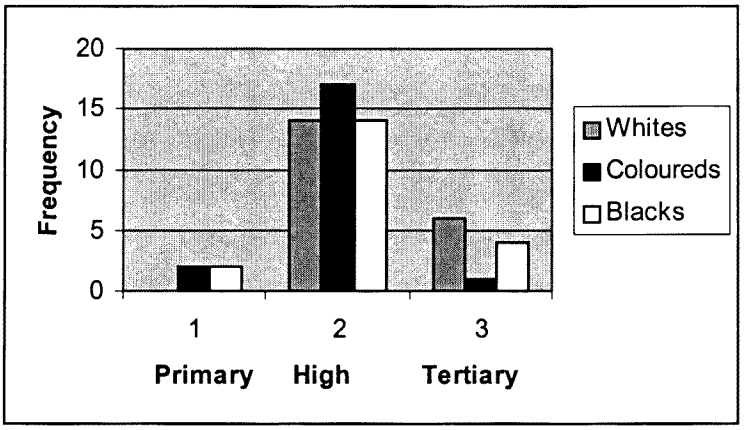

Figure 4.6 Caregivers highest level of education.

4.2.8 Relationship of the caregivers (respondents) with the disabled child

The relationships of the caregivers (respondents) to the disabled children are presented in Figure 4.7. The figure shows that majority of the caregivers were the mothers of the disabled children.

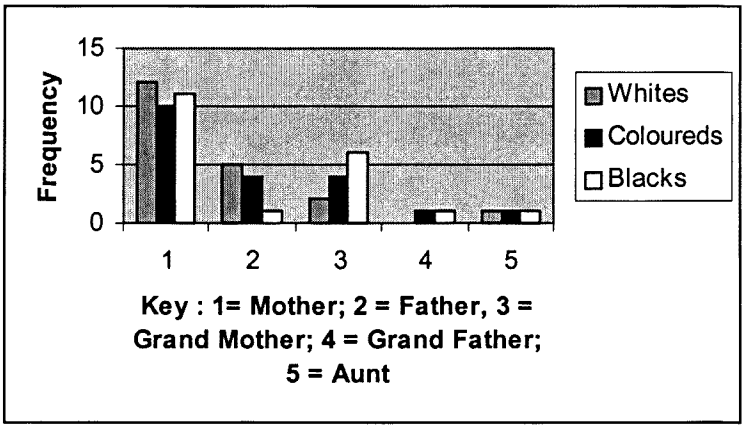

Figure 4.7 Summary of the relationship of caregivers (respondents) to the disabled children.

PART II

4.3 SOCIO-DEMOGRAPHIC DATA OF THE DISABLED CHILDREN

4.3.1 Age groups of the children

Figure 4.8 summarises the age group of the disabled children. The figure shows that the majority of the disabled children are between one and five years old. When data were tested statistically using chi-square test, the differences were found not be significant *(p > 0.05).*

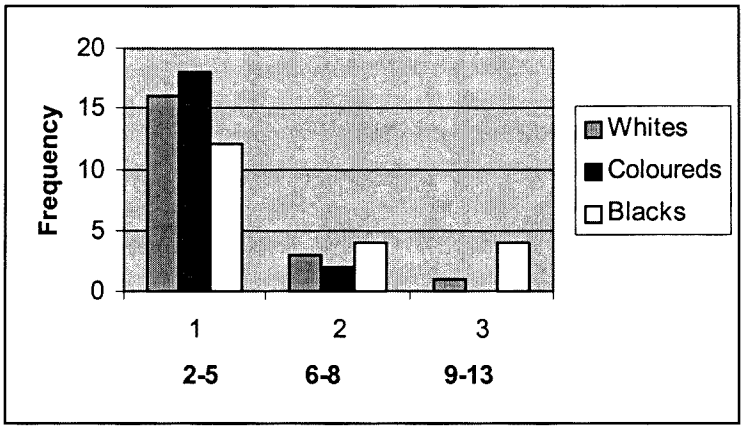

Figure 4.8 Summary of the age groups of the disabled children (n=60)

4.3.2 Gender of the disabled children

The gender profile showed a similar distribution of males to females across the three cultural groups (Whites 9:11; Coloureds 11:9; and Blacks 10:10).

4.3.3 Nature of the disability of the children (partially or totally disabled)

The majority (n = 19) of the Coloured group were partially disabled, followed by the White group (n = 14), and the Black group (n = 12). Of those who were totally disabled the Black group had the highest number (n = 8), followed by the White group (n = 6). There was only one child who was totally disabled in the Coloured group. When assessed using a chi-square test, the differences on the nature of disability were shown to be significant, Pearson chi-square *(2) = 6.933 (p < 0.05).*

4.3.4 Types of physical disability of the children

Figure 4.9 shows a summary of the types of disability the children had. The figure shows that the commonest disability in all the three cultural groups was cerebral palsy.

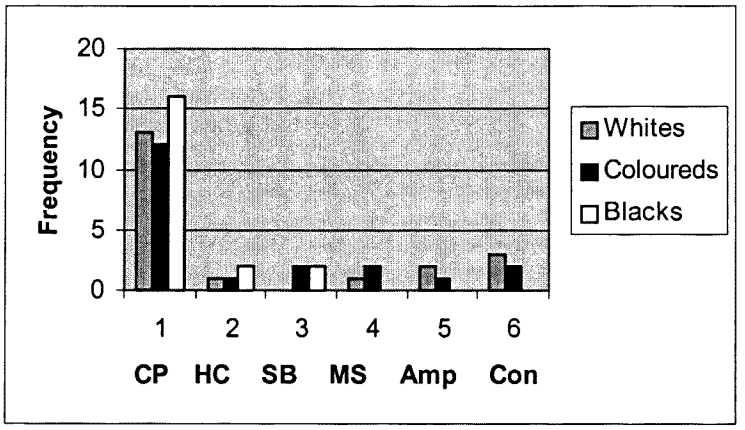

Figure 4.9. Frequencies of types of disability.

(Key: CP= cerebral palsy; HC = hydrocephalus; SB = spina bifida; MD = muscular dystrophy; Amp = amputation; Con = contractures).

PART III

4.4 THE RESULTS OF THE QUESTIONNAIRE

In this section the results of both parts of each question will be presented.

SECTION A: Knowledge about disability

QUESTION 1

A. Have you ever heard or read about disability? Yes….. No…... Not sure…..

A. If yes, when?

Response A

The frequencies of caregivers who had heard or read about disability prior to the study are summarised in Figure 4.10. The figure shows that the majority of the participants in each cultural group indicated that they had heard or read about disability prior to the study. The differences were not significant *($p > 0.05$).*

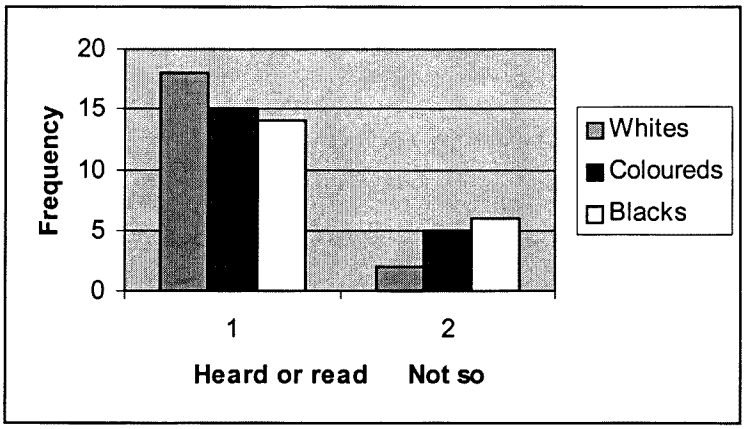

Figure 4.10 Frequencies of caregivers who had heard or read about disability prior to the study.

Response B

The main themes of responses given by those who had answered affirmatively to Question 1A are summarised in Table 4.1. The table shows that most respondents in the Coloured and White groups had been aware of disability from an early age.

Table 4.1 Frequencies of themes from responses given in Question 1B concerning when participants had first heard or read about disability.

Responses	Whites	Coloureds	Blacks	Total
When young	16	11	4	31
Recently	2	3	1	6
After the birth of the child	0	1	9	10
Total	18	15	14	47

QUESTION 2

A. Is there a name for a person with disability in your own language?

Yes….. No….. Do not know…...

B. If yes, specify.

Response A

The majority of the respondents (Whites n = 16; Coloureds n = 16; Blacks n = 15) knew the name (term) for a person with disability in their own language, while the rest did not know a particular name.

Response B

Among those who knew a name (a particular term) for a person with disability in their own language, the Black group had two different names. The majority called disabled persons *"ukhubazeko"* and the others called them *"Isidalwa"*. All the whites (whose home language in this sample was Afrikaans) referred to disabled persons as *"Gestrem"*, this was the same name used by Coloured respondents who were all Afrikaans speaking.

QUESTION 3

A. Have you ever seen anyone with a disability? Yes….. No….. Not sure…..

B. If yes, where ?

Response A

The respondents from all three cultural groups gave similar responses. The majority of the respondents (Whites n = 20; Coloureds n = 19; Blacks n = 19) reported that they had seen someone with a disability. One person each among the Coloureds and Blacks reported that they had not previously seen anyone with a disability.

Response B

Those who had seen someone with a disability reported that they had seen them in the following places:

a) In their communities (Blacks n = 12; Whites n = 10; Coloureds = 7)

b) In various institutions (Whites n = 4; Coloureds n = 4; Blacks n = 2)

c) In their families (Coloureds n = 8; Whites n = 6; Blacks n = 5).

QUESTION 4

A. *Do you have anyone with disability among your relatives?*
   Yes. No. Not sure……
B. *If yes, specify the relationship?*

Response A

Most of the respondents across the three cultural groups (n= 35) reported that they did not have a relative who was disabled (Blacks n = 14; Whites n = 12; Coloureds n = 9). The minority of each group (Blacks n = 6; Whites n = 8; Coloureds n = 11) reported that they have relatives who are disabled. When the data were assessed using the chi-square test, the differences among the three cultural groups were found not to be significant *($p > 0.05$).*

Response B

Among those who reported having disabled relatives the majority reported that they have distant relatives who are disabled, while a few reported that having a close relative who is disabled.

Distant relative (Coloureds n = 9; Blacks n = 4; Whites n = 3).

Close relative (Coloureds & Blacks n = 2 each; Whites n = 5).

QUESTION 5

A. *Do you know anyone else with a disability who is not a relative? Yes….. No….. Not sure….*

Response A

Most of the responses for the three cultural groups were similar. The majority of the respondents (Whites n = 16; Blacks n = 13; Coloureds n = 12) reported that they knew people with a disability who were not related to them. The minority (White n = 4; Coloureds n = 7; Blacks n = 8) reported that they did not know anyone with a disability who is not related to them.

QUESTION 6

A. *Do you have any idea of what causes disability? Yes…. No….. Not sure…..*

B. If yes, explain.

Response A

The majority of the respondents in each cultural group (Whites & Coloureds n = 16 each; Blacks n = 12) indicated that they had an idea of what caused disability. Among those who reported not having any idea of what caused disability were (Whites and Coloureds n = 4; Blacks n = 8). When assessed using the chi-square, the differences from the data from the three cultural groups were not statistically significant *($p > 0.05$).*

Response B

The themes of responses from the respondents who indicated that they had an idea of what causes disability are presented in Table 4.2. The table shows that the most popular response was “illness”.

Table 4.2 Summary of frequencies of themes concerning what causes disability.

Responses	Whites	Coloureds	Blacks	Total
Accidents	6	3	1	10
Illness	4	3	4	11
Problem during pregnancy	0	3	4	7
Drugs and alcohol	2	2	0	4
Difficult labour	1	1	3	5
Lack of immunization	1	1	0	2
Premature labour	1	1	0	2
Wrong medication during pregnancy	0	1	0	1
Inheritance	1	1	0	2
Total	16	16	12	44

QUESTION 7

A. Does disability run in families? Yes….. No….. Not sure…..

B. Explain.

Response A

The respondents who indicated that disability does not run in families were as follows: (Coloureds n = 11;Whites and Blacks n = 9 each). The minority disagreed with the statement (Whites n = 8; Coloureds & Blacks n = 9 each). The remaining respondents were not sure of the answer (Whites n = 3; Blacks n = 2). When the differences among the three groups were assessed using the chi-square test, they were found not to be significant *($p > 0.05$).*

Response B

Those who said disability does not run in families gave the following responses:

a) "It is natural" (Whites n = 7; Coloureds n = 8; Blacks n = 4

b) "It is made by God" (Whites n =2; Coloureds n = 3; Blacks n = 5)

The respondents who agreed with the statement gave this response:

"It is acquired from someone" (Whites n = 8: Coloureds & Blacks n = 9 each)

QUESTION 8

A. *Do you think disability is contagious? Yes….. No…. Do not know……*
B. *Explain.*

Response A

The three cultural groups responses were almost identical. All the groups (Whites & Coloureds n = 20 each; Blacks n = 19) responded affirmatively. Only one Black respondent did not know whether disability was contagious or not.

Response B

The respondents who responded affirmatively to Question 8A gave these explanations:

a) "It is not a disease" (Whites n = 20; Blacks n = 19; and Coloureds n = 14)
b) "It is due to brain dysfunction" (Coloureds n = 4)
c) "It is something that one is born with" (Coloureds n = 2).

The single Black respondent who did not know the answer to Question 8A, also did not have an explanation to Question8 B.

SECTION B: Attitudes and beliefs about disability

Question 9

A. *Disability is a man made disease.*
   Strongly agree….. Mildly agree….. Mildly agree….. Mildly disagree….. Strongly disagree.
B. *Explain.*

Response A

The responses to Question 9A are summarised in Table 4.3. According to the table, the majority of both Coloureds and Whites generally disagreed with the statement

"disability is a man-made disease". When assessed using chi-square, the differences across the three cultural groups were found to be significant (Pearson chi-square *(8) = 24.977, p < 0.01)*

Table 4.3 Frequencies from responses to Question 9A concerning whether disability is a man-made disease.

Responses	Whites	Coloureds	Blacks	Total
Strongly agree	1	0	8	9
Mildly agree	6	2	5	13
Mildly disagree	2	1	0	3
Strongly disagree	10	12	7	29
Don't know	1	5	0	6
Total	20	20	20	60

Response B

The respondents who concurred with the statement "disability is a man-made disease" gave the following themes of explanations:

a) "From human errors" (Whites n=7; Coloureds n=8).

b) "From witchcraft" (Blacks n=8).

a) "Ill treatment of the spouse" (Blacks n=3).

b) "Ill treatment of the child" (Blacks n=1)

Those who did not concur with the statement gave these explanations:

a) "Beyond man's power (spirits)" (Whites n = 4; Coloureds n = 4; Blacks n =7)

b) "Natural causes (Coloureds n = 7; Whites n = 8; Blacks n = 1).

One White and one Coloured did not know the answer to that is question.

QUESTION 10

A. Disability is a disease from God.

Strongly agree….. Mildly agree….. Mildly disagree…… Strongly disagree…..

B. Explain.

Response A

The number of the respondents who agreed with the statement "disability is a disease from God" were roughly equal for the three cultural groups (Whites n = 11; Coloureds n = 13; Blacks n = 15). Among those who disagreed Whites (n = 9) were in the majority, followed by the Coloureds (n = 7) and then Blacks (n = 5).

Response B

The respondents who agreed with the statement gave the following explanations:

a) "Everything is from God" (Blacks n= 6; Whites n=5; Coloureds n = 5).
b) "God plans everything" (Coloureds n = 3; Whites n = 4; Blacks = 5)
c) "God's blessing" (Whites n = 2;Blacks n=4; Coloureds n = 5)

The themes of explanations given by respondents who disagreed with the statement in Question 10A are summarised in Table 4.4. The table shows that the most popular response of those who disagreed with it was "God can't give bad things to His children".

Table 4.4 Frequencies of themes from of explanations given by those who disagree with the statement in Question 10A..

Responses	Whites	Coloureds	Blacks	Total
God can't give bad things to His children	6	4	2	12
Human errors	3	3	0	6
Witchcraft	0	0	3	3
Total	9	7	5	21

QUESTION 11

A. *Is it a good idea to have hope that your disabled child will be cured? Very bad idea….. Bad idea….. Good idea….. Very good idea….. Do not know….. Not sure.*
B. *Explain.*

Response A

Table 4.5 presents the responses given to Question 11A. According to the table, almost all the respondents indicated that it was a good or very good idea to hope that the disabled will be cured.

Table 4.5 Frequencies from responses to Question 11A

Responses	Whites	Coloureds	Blacks	Total
Very bad idea	2	0	0	2
Bad idea	1	0	0	1
Good idea	7	9	14	30
Very good idea	10	10	6	26
Don't know	0	1	0	1
Not sure	0	0	0	0
Total	20	20	20	60

Response B

The respondents who agreed that it was a good or very good idea to hope that a disabled child would be cured gave the following themes of explanation:

a) "God helps" (Blacks n = 5; Whites & Coloureds n = 4 each)
b) "Hope gives strength" (Whites n = 11; Blacks n = 8; Coloureds n = 7)
c) "Treatment and God can help" (Whites & Coloureds n=1 each)
d) "Treatment can help" (Blacks n = 7; Coloureds n = 5; Whites n = 2).

The minority (Whites n = 3) who suggested that it was a bad or very bad idea to hope that the disabled child will be cured said "Nothing will work out". One Coloured respondent was not sure of the answer.

QUESTION 12

A. *You always feel sorry when seeing someone with disability.*
   Strongly agree….Mildly agree….Mildly disagree…..Strongly disagree…..
   Do not know.
B. *Why?*

Response A

The number of respondents who concurred with the statement "you feel sorry when seeing someone with disability" were equally high for the three groups (Coloureds & Blacks n = 16 each; Whites n = 15). Similarly, the responses of those who did not concur with the statement were also about the same (Whites n = 5; Coloureds & Blacks n = 4 each).

Response B

The themes of responses of those who were in agreement with the statement in Question 12A are summarised in Table 4.6.

Table 4.6 Frequencies of themes from explanations of those who concurred with the statement in Question 12 A

Responses	Whites	Coloureds	Blacks	Total
People involved in disability struggle	5	3	2	10
Because it can happen to anybody	0	0	2	2
Because they don't live a normal life	2	3	2	7
Because they always need help	4	5	4	13
If they don't accept it	1	2	1	4
People make fun of them	1	1	0	2
Total	15	16	16	47

Those who did not concur with the statement in Question 12A gave the following explanations:

a) "It is a blessing" (Coloureds n = 2; Whites n = 1; Blacks n = 2)

b) "It happened for a reason" (Whites n = 2; Coloureds n = 1; Blacks n = 2)

c) "Because they are capable of taking care of themselves" (Whites n = 2); Coloureds n = 1).

QUESTION 13

A. Besides needing help with some physical activities, disabled people are different from other people. Strong agree…..Mildly agree…..

Mildly disagree….. Strongly disagree ….. Do not know.

B. Why?

Response A

Most of the respondents (n = 36) disagreed with the statement (Whites n= 15; Coloureds n= 11; Blacks n= 10). Those who agreed were (Blacks n = 10; Coloureds n = 9; Whites n = 5). When the chi-square test was used to assess the differences, they were found not to be significant *($p > 0.05$).*

Response B

The themes from the respondents who did not concur with the statement in Question 13A are summarised in Table 4.7 below. The table shows that the most popular theme in their responses was "they are equal to us".

Table 4.7 Frequencies of explanation of the respondents who did not agree with the statement that disabled people are different from other people (besides needing help with physical disability)

Responses	Whites	Coloureds	Blacks	Total
They are equal to us	10	8	8	26
They can do something with their disability	4	3	2	9
They are more challenged than other people	1	0	0	1
Total	15	11	10	36

Those who did not agree with the statement gave the following themes in their responses:

a) "They need help in daily activities" (Blacks n = 7; Coloureds n=4; Whites n= 2)

b) "They don't do things like other people" (Whites n=1; Coloureds n=1)

c) "They don't understand like other people" (Coloureds n=4; Blacks n=3; Whites n=2).

QUESTION 14.

A. your disabled child should not marry. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know…..

B. Why?

Response A

The responses to Question 14A are summarised in Table 4.8. According to the table, a majority in each of the three cultural groups generally disagreed with the statement "Your disabled child should not marry".

Table 4.8 Summary of responses to Question 14A

Responses	Whites	Coloureds	Blacks	Total
Strongly agree	1	1	3	5
Mildly agree	6	3	3	12
Mildly disagree	3	2	2	7
Strongly disagree	9	13	12	34
Don't know	1	1	0	2
Total	20	20	20	60

Response B

Table 4.9 presents the themes of explanation given by the respondents who disagreed with the statement in Question 14A. The table shows that the most favoured theme was that disabled people "Have a right to enjoy life".

Table 4.9 Frequencies of themes of explanation in response to the statement "your disabled child should not marry".

Responses	Whites	Coloureds	Blacks	Total
It is their choice	4	5	1	10
Have a right to enjoy life	6	6	0	12
They can manage in marriage like other people	1	0	2	3
They also have feelings	1	3	1	5
It is their right	0	0	6	6
Spouse will assist the disabled	0	0	4	4
Total	12	14	14	40

Those who disagreed with the statement gave the following two themes of explanations:

a) "If severely disabled they are dependent on other people" (Whites n = 5; Blacks n = 4; Coloureds n = 3).

b) "Nobody wants to marry a disabled person" (Coloureds n = 1; Blacks n = 2; Whites n = 2).

One Coloured and one White respondent did not give an answer.

QUESTION 15

A. *You are afraid of disabled people. Strongly agree….. Mildly agree….. Mildly disagree…… Strongly disagree….. Not sure.*

B. Why?

Response A

Most of the respondents did not agree with the statement "You are afraid of disabled people". The majority who disagreed with it were (Whites n = 20; Blacks and Coloured n = 19 each). Only two respondents (Coloured n = 1; Blacks n = 1) agreed with it.

Response B

Table 4.10 summarises the themes of explanations given by the respondents who answered affirmatively to Question 15A. According to the table, the most popular response was "they are human beings".

Table 4.10 Frequencies of themes from explanations in response to Question 15A regarding fear of disabled people.

Responses	Whites	Coloureds	Blacks	Total
I have a disabled child	2	4	6	12
They are harmless	5	6	2	13
They are human	12	9	10	31
They didn't choose to be disabled	1	0	1	2
Total	20	19	19	58

There were only two respondents (Coloureds & Blacks n = 1 each) who agreed with the statement in Question 15A, and their reason was "they can hit you".

QUESTION 16

A. *Your child who is not disabled should not marry a disabled person. Strongly agree…. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know…..*

B. *Why?*

Response A

The majority (n = 44) of the respondents disagreed with the statement in Question 16A. Almost all the Coloured respondents (n =19), except one who did not answer, disagreed with it, as did most of the Whites (n = 17) and Blacks (n = 15). Only a minority (Black n = 5; White n = 3) concurred with the statement. When assessed using the Chi-square test, the differences were not significant *($p > 0.05$)*.

Response B

Those who disagreed with the statement supported their answers with the following themes of explanations:

a) "It is their choice" (Whites n = 17; Coloureds n = 13; Blacks n = 10).
b) "Normal person should be able to take care of the disabled" (Blacks n = 2; Coloureds n = 1).
c) "They are human beings and they have a right to marry" (Blacks n = 3; Coloureds n = 5).

The few who disagreed with it gave these two themes of explanations:

a) "Normal person should marry a normal person" (Blacks n = 2; Whites n = 1).
b) "Non disabled will take advantage of the disabled person" (Black n = 3; White n = 2).

QUESTION 17

A. People with disability should not have children. Strongly agree….. Mildly agree….. mildly disagree….. Strongly disagree….. Do not know.

B. Why?

Response A

The responses to the statement "people with disability should not have children" are presented in Table 4.11.The table shows that across the three cultural groups, of those who agreed the Whites were in the majority. When the difference among the three cultural groups were statistically assessed using the chi-square test, they were found not to be significant *($p > 0.05$).*

Table 4.11 Frequencies of themes from Question 17A concerning whether disabled people should have children

Responses	Whites	Coloureds	Blacks	Total
Strongly agree	1	4	3	8
Mildly agree	0	1	0	1
Mildly disagree	8	3	3	14
Strongly disagree	11	12	14	37
Don't know	0	2	2	4
Total	20	20	20	60

Response B

The themes of explanations given in response to Question 17A are summarised in Table 4.12. The table shows that most of the respondents who disagreed with the statement responded "it's their choice".

Table 4.12 Frequencies of themes from responses of those who agreed that disabled people should have children

Responses	Whites	Coloureds	Blacks	Total
It's their choice	9	3	3	15
The children will look after the disabled	0	1	5	6
They also have feelings	0	3	4	7
They are capable of taking care of them	6	2	1	9
They are productive like other people	0	1	4	5
They must get medical advice first	4	5	0	9
Total	19	15	17	51

All the respondents who disagreed with the statement (Coloureds n = 3; Blacks & Whites n = 1 each) gave similar reasons along the theme of "If severely disabled they depend on other people".

QUESTION 18

A. If you happen to be the manager of a company, you would not employ disabled persons in your company. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know.

B. Explain why?

Response A

Most respondents (Coloureds n = 19; Whites & Blacks n = 17 each) generally disagreed with the statement. The Whites and Blacks again had almost equal numbers of respondents (n = 3 each) who concurred with the statement. There was only one Coloured respondent who agreed with it.

Response B

Table 4.13 presents the themes of the explanations of respondents who agreed with the statement in Question 18B.

Table 4.13 Frequencies of themes from responses of the respondents who were in support of employing disabled people.

Responses	Whites	Coloureds	Blacks	Total
If not severely disabled they can do the job	4	7	5	16
If they meet the requirement	7	4	5	16
They also have a right to work	3	4	4	11
They have needs	2	2	2	6
They need to be empowered	1	2	1	4
Total	17	19	17	53

The few (n = 7) who disagreed with this statement gave the following two themes of explanations:

a) "If severely disabled they cannot work" (Whites n = 2; Blacks n = 1).

b) "They cannot do things properly" (Blacks n = 2; Whites n = 1; Coloureds n = 1).

QUESTION 19

A. *People with disability should not be allowed to be in charge of the company. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know.*

B. *Why?*

Response A

The majority (n = 54) of the respondents disagreed with the statement in Question 19A. Those who disagreed with the statement were (Whites n = 19; Blacks n = 18; Coloureds n = 17). Very few respondents (Coloureds & Blacks n = 2 each; Whites n = 1) agreed with the statement. The remaining Coloured respondent did not answer this question.

Response B

Those who disagreed with the question supported their statement with the following themes of explanations:

a) "If they have confidence" (Whites n= 19; Blacks n= 16, Coloureds n= 16).
b) "It's their right" (Blacks n= 2; Whites & Coloureds n = 1 each).

Those who answered affirmatively to Question 19A gave the following themes of explanations:

a) "They cannot do things well" (Blacks n = 2; Whites n = 1; Coloureds n = 2 each)
b) "Nobody wants a disabled manager" (Coloured – n= 1),

Question 20

A. *Families having disabled people should completely hide them. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know…..*

B. *Why?*

Response A

All the respondents (n = 60) in the three cultural groups strongly disagreed with the statement "families having disabled people should completely hide them".

Response B

The frequencies of themes from explanations given by respondents to Question 20B are summarised in Table 4.14. The table shows that the most favoured theme was "they should be accepted".

Table 4.14 Frequencies of themes from explanations in response to Question 20A in regard to whether families should completely hide their children from society.

Explanation	Whites	Coloureds	Blacks	Total
They should be accepted	4	9	4	17
They need to be treated like other people	7	2	5	14
They are human beings like us	5	3	4	12
They need to know what is happening around them	3	2	4	9
You will not get help from other people if you hide them	0	0	2	2
They should socialise	1	4	1	6
Total	20	20	20	60

QUESTION 21

A. *Disabled persons should associate with the other members of the community. Strongly agree…..Mildly agree….. Mildly disagreed ……. Strongly disagree….. Do not know.*

B. *Why?*

Response A

The majority of respondents (Blacks n = 20; Whites & Coloureds n = 18 each) were predominantly supportive of the statement that "disabled persons should associate with the other members of the community". Only a few respondents (Whites and

Coloureds n= 2; each) were not in agreement with this.

Response B

Themes of the explanations of those who agreed that the disabled persons should associate with other members of the community are summarised in Table 4.15. The table shows that the most popular theme was "they can learn and contribute to the community".

Table 4.15 Frequencies of themes from explanations of respondents who agreed that disabled people should associate with other member of the community.

Response	Whites	Coloureds	Blacks	Total
Feel accepted	5	4	8	17
They can learn and contribute to the community	6	6	5	17
They need to socialise	3	5	2	10
They will be empowered	4	3	5	12
Total	18	18	20	56

The remaining respondents (Black & Coloured n = 2) who did not support the statement said, "they will be ill-treated".

QUESTION 22

A. *Persons with disability should not be allowed to use public transport. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know…..*

B. *Explain.*

Response A

With regard to not allowing disabled people to use public transport, the majority of the respondents (n = 36) disagreed with the idea. There were generally similar frequencies of responses among those who did not agree with the statement (Whites, Blacks & Coloureds n = 12 each). Of the minority (n = 24) who agreed with the statement, there was an equal distribution of responses (n = 8 each) over the

three cultural groups.

Response B

Table 4.16 presents the themes of explanations of the respondents who did not concur with the statement in Question 22A. The table shows that the most popular theme was "if they are capable".

Table 4.16 Frequencies of themes from the respondents who disagreed with the statement in Question 22A

Explanation	Whites	Coloureds	Blacks	Total
If they are capable	7	7	4	18
It is their right	5	4	3	12
They don't have personal transport	0	1	5	6
Total	12	12	12	36

The respondents who were in agreement with the statement gave the following themes of explanation:

a) "Public transport does not respect them" (Whites n = 6; Coloureds n = 4; Blacks n = 5).
b) "They can be injured" (Coloureds n = 3; Whites & Blacks n = 2 each).
c) "If severely disabled" (Coloureds & Blacks n = 1 each).

QUESTION 23

A. If after seeing a doctor you are informed that your child cannot walk, talk or see, is it necessary to take a child for any other medical services. Absolutely unnecessary..... Unnecessary..... Necessary..... Very unnecessary..... Do not know..... Not sure.

B. Explain.

Response A

The responses to Question 23A are shown in Table 4.17. The table shows that the majority of participants said it was necessary to take the child for other medical services. The next largest group (15 out of 60) felt it was unnecessary. When assessed using a chi-square test, the differences among the three cultural groups' responses were not significant *(P > 0.05).*

Table 4.17 Frequencies of responses to Question 23A

Response	Whites	Coloureds	Blacks	Total
Absolutely unnecessary	1	2	4	7
Unnecessary	4	7	4	15
Necessary	13	6	10	29
Very necessary	2	4	2	8
Not sure	0	1	0	1
Total	20	20	20	60

Response B

When responding to why it was necessary to take the child for other medical services, the following themes of explanations were given:

a) Seek second opinion (Whites n = 15; Blacks n= 8; Coloureds n = 7).

b) Keep on looking for help every time (Blacks n = 4; Coloureds n = 2). However, there was only one Coloured respondent who was not sure.

The respondents who said it was absolutely unnecessary to take a disabled child for any other medical services gave only one theme of explanation,

a) "Believe what doctors say" (Coloureds n = 9; Blacks n = 8; Whites n = 5).

QUESTION 24

A. It is a good idea to take the disabled child to other healers besides the western(hospital) healers (e.g. religious or traditional healers). Worst idea… Bad idea….. Good idea….. Best idea….. Do not know….. Not sure.

B. Explain.

Response A

Table 4.18 presents a summary of responses to Question 24A. According to the table, there was an equal distribution of respondents across the three cultural groups who said that it was a bad idea to take a disabled child to other healers besides western (hospital) healer.

Table 4.18 Frequencies of responses to Question 24A

Response	Whites	Coloureds	Blacks	Total
Worst idea	4	0	1	5
Bad idea	8	11	10	29
Good idea	4	6	7	17
Best idea	1	0	2	3
Don't know	3	0	0	3
Not sure	0	3	0	3
Total	20	20	20	60

Response B

The themes of the explanations given in response to Question 24B are presented in Table 4.19. The table shows that the most popular theme was "pray and rely on doctors".

Table 4.19 Frequencies of themes of explanations regarding taking the disabled child to other healers besides the western healers (e.g. religious or traditional healers).

Explanation	Whites	Coloureds	Blacks	Total
Pray to God and rely on doctors	7	8	6	21
Rely on doctors	4	2	3	9
Healers don't help	1	1	2	4
Total	12	11	11	34

Those who said it is a good idea or the best idea to see healers gave the following themes of explanation:

a) "Rely on doctors as well as religious healers" (Whites n = 2; Coloureds n = 4; Blacks n = 1).

b) "Rely on doctors as well as traditional healers" (Blacks n = 7).

c) "Rely on religious healers" (Whites n =3; Coloureds n = 2; Blacks n = 1).

The remaining three respondents in the White and Coloured groups were not sure.

QUESTION 25

A. Parents of children with a disability should have an opportunity to give an opinion and participate in the treatment of their disabled children. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know.

B. Explain?

Response A

In terms of parents participation in the treatment of their disabled children, the majority of respondents (n = 51) were strongly in support of the idea. There were equal frequencies of responses for each grouping (Whites; Coloureds & Blacks n = 17 each). A similar pattern occurred with those who disagreed with the statement (3 in each group).

Response B

The themes of explanations given in response to Question 25B are summarised in Table 4.20. The table shows that the most popular response was "To help each other on treatment".

Table 4.20 Summary of themes from explanations given by respondents who agreed with the statement in Question 25A.

Explanation	Whites	Coloureds	Blacks	Total
Help the child to improve	0	4	4	8
Make work easy for doctors and therapists	1	1	0	2
Must know what is done to the child	8	0	2	10
The mothers stay with the children and know their needs	3	6	3	12
To help each other on treatment	5	6	8	19
Total	17	17	17	51

Three respondents from each of the three cultural groups found it unnecessary to participate in the treatment of their disabled children .The theme of their explanation was, "the doctors know better than us".

QUESTION 26

A. *What are the chances of taking your disabled child for regular treatment? Very good chance….. Good chance….. Small chance….. Very small chance….. Do not know…… Not sure.*

B. Why?

Response A

When asked about the chance of taking their disabled children for regular treatment, the majority (n = 47) said either there was a good or a very good chance of this happening (Whites and Coloureds n = 17 each; Blacks n = 11). Few respondents (Blacks n = 9; Coloureds & Whites n = 3 each) said that there was a small chance of their doing so. When the differences were assessed statistically using a chi-square test, the differences were not significant *($p > 0.05$.*

Response B

When explaining why they would take their disabled children for regular treatment, the respondents gave the following reasons:

a) "Because I want my child to get help" (Coloureds n = 10; Whites n = 8; Blacks n = 2)
b) "Because I want my child to improve" (Whites & Blacks n = 9 each; Coloureds n = 7).

Among those who said there was a small chance of doing so gave reasons with the following themes:

c) "Because doctors need that" (Blacks n = 4; Whites n =3; Coloureds n = 1).
d) "Because of lack of money" (Blacks n = 4; Whites & Coloureds n = 2 each)
e) "It is waste of time" (Blacks n = 1).

QUESTION 27

A. *Disabled children should not attend school. Strongly agree…. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know.*
B. *Why?*

Response A

In responding to the statement "disabled children should not attend school", all the respondents (n = 20) disagreed with the statement.

Response B

The respondents gave the following themes of explanation for the above result:

a) "They need to learn" (Blacks n = 19; Coloureds n = 18; Whites n = 13)
b) "If disability is not severe they can learn too" (Whites n = 3; Coloureds n = 2; Blacks n = 1)
c) "They need stimulation" (Whites n = 4).

QUESTION 28

A. Disabled children should have their own schools. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know.

B. Why?

Response A

Responding to the statement "disabled children should have their own schools", the majority of the respondents (N = 43), (Blacks n= 18; Coloureds n= 15; Whites n=10) agreed. The minority (White n = 10; Coloureds n = 5; Blacks n = 2) disagreed with the statement. When assessed using the chi-square test, the differences among the three cultural groups were shown not to be significant ($p > 0.05$).

Response B

The themes of explanations to Question 28A are presented in Table 4.21. According to the table, the most popular theme of explanations was "if severely disabled they need special teachers",

Table 4.21 Summary of themes of explanations given by respondents who disagreed with the statement in Question 28A.

Explanations	Whites	Coloureds	Blacks	Total
If severely disabled they need special teachers	6	4	4	14
In regular schools other children and teachers will make fun of them	2	5	6	13
In their own schools they will be accepted the way they are	2	2	1	5
Regular schools don't take care of them	0	4	6	10
Children in regular schools will hit them	0	0	1	1
Total	10	15	18	43

The respondents who did not concur with this statement, reasoned this way:

a) "If the disabled children are able to learn in regular schools they should attend them" (Coloureds n = 3; Whites n = 5; Blacks n = 2).
b) "Regular schools will empower them" (Whites n = 5; Coloureds n = 2).

QUESION 29

A. Is it a good idea for the parents of disabled children to participate in the planning of their children's education? Very bad idea….. Bad idea….. Good idea….. Very good idea….. Do not know….. Not sure.

B. Why?

Response A

When asked if it was a good idea for the parents of disabled children to participate in their childrens' education, (Whites & Coloureds n = 20 each; Blacks n = 16) said that either it was a good or very good idea to do so. Very few respondents (n = 3) from the Black cultural group said it is a bad idea to do so. One Black respondent was not sure of the answer. When assessed using chi-square test, the differences among all the three cultural groups were found not to be significant ($p > 0.05$).

Response B

The respondents who said it was either a good or very good idea for parents to participate in the education of their disabled children gave the following themes of explanations:

a) "Parents need to know the needs of their children" (Whites n = 8; Coloureds n = 5; Blacks n = 2)
b) "Parents can help the teachers because they know the children better" (Blacks n = 6; Coloureds n = 5; Whites n = 3).
c) "They must know the progress of their children" (Coloureds n = 6; Blacks n = 5; Whites n = 8).
d) "It is good to participate in your child's life" (Coloured – n = 4; Blacks n = 3; Whites n = 1).

Those who said it was a bad idea to do so (Blacks n = 3), gave this explanation:

"Parents are not teachers, they do not know what is right about school" as the main reason. One Black respondent did not answer the question.

QUESTION 30

A. *Disabled children should participate in sports. Strongly agree….. Mildly agree….. Mildly disagree….. Strongly disagree….. Do not know.*

B. *Explain.*

Response A

The results showed that the majority (N = 59) across all three cultural groups concurred with the statement "disabled children should participate in sports". There was only one Black participant who strongly disagreed with that statement

Response B

The themes of explanations given in response to Question 30A are summarised in Table 4.22. The table shows that most respondents said that sports help the children to exercise.

Table 4.22 Summary of themes of explanations given to support the statement in Question 30A.

Explanations	Whites	Coloureds	Blacks	Total
Help them to exercise	5	7	11	23
Sports motivate them	10	5	4	19
Keeps them healthy	4	6	4	14
It's fun for them	1	2	0	3
Total	20	20	19	59

One Black respondent said sports were dangerous for disabled children.

QUESTION 31

A. Disabled persons are inferior. Strongly agree…..Mildly agree…. Mildly disagree…..Strongly disagree….. Do not know.

C. Explain.

Response A

When asked if disabled persons were inferior, a large majority of respondents (N = 55) in the three cultural groups disagreed. Most, (Blacks n =20; Whites n = 19; Coloureds n= 16) did not concur with that statement. Very few respondents (Whites n = 1; Coloureds n = 3) agreed with this, while the remaining one Coloured did not know. When the differences among the three cultural groups were assessed statistically using chi-square test, they were not significant ($p > 0.05$).

Response B

Table 4.23 presents the themes of explanations given by the respondents who disagreed with the statement in Question 31A. The table shows that the majority of respondents said that disabled people are like other people.

Table 4.23 Summary of the themes of responses given by respondents who disagreed with the statement Question 31A.

Explanations	Whites	Coloureds	Blacks	Total
They are like other people	12	11	12	35
They can do something with their life	4	3	2	9
They are a gift from God	1	1	2	4
They are important	1	1	2	4
They are superior	1	0	2	3
Total	19	16	20	55

The few respondents who disagreed with the statement in Question 31A indicated that "disabled people did not do things like other people" (Whites n = 1 & Coloureds n= 3). The remaining three Coloureds did not know nor provide any explanation.

QUESTION 32

A. *How much do your relatives like your disabled child? Very much…..*

Much….. Dislike….. Dislike very much….. Do not know….. Not sure.

B. Explain.

Response B

Most respondents (Coloureds n= 20; Whites n= 18; Blacks n = 13) indicated that their relatives liked their disabled children very much. Among those who expressed that their relatives disliked their disabled children were (Blacks n = 6; Whites n = 1). One Black respondent did not know the answer while one White respondent was not sure of the answer. When assessed using chi-square test, the differences across the three cultural groups were shown not to be significant ($p > 0.05$).

Response B

The themes of the explanations given by the respondents who said their disabled children were liked very much by their relatives are summarised in Table 4.24.

Table 4.24 Summary of the themes from the explanations of the respondents who indicated that their relatives liked their disabled children.

Explanations	Whites	Coloureds	Blacks	Total
They treat the child like other children	6	7	5	18
They do things which make the child happy	5	3	4	12
They help the child to do things	4	2	4	10
They give the child special attention	1	4	2	7
They take care of the child	2	4	0	6
Total	18	20	15	53

The respondents who indicated that their relatives disliked their disabled children (Blacks n = 5; Whites n = 2) gave the explanation that they do not help the child with anything.

QUESTION 33

A. How well does the society help disabled people? Very well….. Well…..

Not well….. Not very well….. Do not know….. Not sure.

B. Explain.

Response A

The responses to Question 33A are summarised in Table 4.25. According to the table, most respondents indicated that society does not help disabled people much. When assessed using the chi-square test, the differences were not significant ($p > 0.05$).

Table 4.25 Summary of frequencies of responses to Question 33A.

Response	Whites	Coloureds	Blacks	Total
Very well	1	1	4	6
Well	4	7	5	16
Not well	4	4	4	12
Not very well	7	4	4	15
Do not know	2	2	3	7
Not sure	2	2	0	4
Total	20	20	20	60

Response B

The themes of explanations to Question 33A are presented in Table 4.26. The table shows that among those who indicated that society did not help disabled people their most popular theme of explanation was "they don't care about disabled people".

Table 4.26 Summary of the themes of the explanations of respondents who indicated that society does not help disabled people.

Explanation	Whites	Coloureds	Blacks	Total
They don't care about disabled people	7	6	1	14
They ill-treat disabled people	1	2	5	8
They refuse to sponsor them	2	0	1	3
They don't want to socialise with them	0	0	1	1
Total	10	8	8	26

Those who said society does help disabled people gave the following reasons:

a) "They sponsor them" (Black & Coloureds n = 4; Whites n = 1).

b) "They help them to do some activities" (Whites n = 3; Blacks n = 2; Coloureds n = 2).

c) "They take care of them" (Blacks n = 3; Coloureds n = 2; Whites n = 1).

Two Coloured respondents, two White respondents and three Black respondents said they did not know, while two Coloured respondents and two White respondents were not sure.

QUESTION 36

If you wake up in the morning and you find yourself president of this country, what would you do for the disabled people?

The themes obtained from responses to this question are summarised in Table 4.27. The table shows that the main priorities of the respondents from all three cultural groups were education, rehabilitation, transport and disability grants.

Table 4.27 Summary of themes of what the respondents would do for disabled children if they had political power.

Response	Whites	Coloureds	Blacks	Total
Provide education for the disabled children	18	13	14	45
Provide therapy for every disabled child	15	11	11	37
Give them a disability grant	9	12	11	32
Provide transport	6	9	12	27
Build homes for them	5	9	12	26
Meet their needs	7	8	3	18
Allow equal opportunity in everything	9	5	3	17
Provide them with other medical professionals	11	3	2	16
Make every building accessible to them	6	5	2	13
Create jobs for disabled people	4	4	4	12
Employ people to take care of them	2	3	6	11
Give assistance and advice	2	3	6	11
Make a constitution which will favour them	6	3	1	10
Build hospitals for them	3	3	2	8
Give them emotional support	3	2	2	7
Build sports centres for them	4	1	1	6
Give them food	0	1	3	4
Give them free medication	0	2	0	2
Build a special church for them	0	1	0	1

4.5 OVERVIEW OF THE CHAPTER

The chapter presented the demographic data of the children with disability and their caregivers. The chapter also covered the presentation of results on knowledge, attitudes and beliefs towards disability. The quantitative data, representing the responses to the closed questions (i.e. all A responses) were presented first. Lastly the qualitative data (all B responses for the corresponding questions) were interpreted in the form of themes.

****

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

In this chapter I will first discuss the demographic data of the caregivers (that is, the respondents) and the disabled children, followed by the knowledge, attitudes and beliefs of the three cultural groups towards disability.

Part 1

5.2 SOCIO-DEMOGRAPHIC DATA OF CAREGIVERS (RESPONDENTS) OF THE CHILDREN WITH DISABILITY

5.2.1 Introduction

The following variables were identified from the socio-demographic characteristics: age, gender, religion, marital status, number of children the parents of a disabled child have, the highest level of education of the caregiver, the relationship of the caregiver to the child with disability, the degree of disability and the type of disability of the child. Some of the variables will be discussed in groups and others individually.

5.2.2 Relationship, age and the level of education

The majority (N = 33) of the caregivers in all three cultural groups were mothers who were mostly between the ages of 20 and 40 years.

Several studies relate to the time when the child has reached adolescence and the family is dealing with issues related to the child's independence and leaving home (for example, Wikler, 1986, Quine & Pahl, 1989). The literature also reveals that adolescence to adulthood is a more stressful time for the disabled person (Dorner, 1975). It was found that during this time parents have to cope with increased daily stress and all worried about how their children will behave and cope with the outside world. Dorner (1975) observed that parents of adolescents and young adults with severe disabilities often see this period as a particularly stressful time. For many

parents the responsibilities for their physically disabled child will increase rather than decrease with the child's age, as will the burden of care (Meyer,1986). Considering the literature, it is also reasonable to assume that they did not bring them because the burden of care had increased as some of the children may be going though physiological changes, for example, in the case of female children the caregivers have to deal with menstrual periods and so on, which places an extra burden on them. It may also be argued that transporting older children is more difficult for caregivers especially for those who use public transport. Most of the caregivers highlighted transport as one of their top priorities in Question 36 when they were asked what would they do for children with disability if they were President of South Africa.

With respect to education, the results showed that only four respondents among the three cultural groups had primary education. The rest had at least some high school education and some had tertiary education. Quine and Pahl (1991) point out that high levels of education allow increased access to information and more sophisticated problem-solving skills. Since the majority of the respondents had some high school education and some tertiary education, this may have influenced their interest in the health and care of the child with disability.

5.2.3 Gender

Most of the men who brought their children for therapy had accompanied their spouses; very few had come on their own. It could be argued that males are disinclined to care for the sick and the disabled. Howell (1973) points out that some fathers hold down two or more jobs to finance care for the disabled child. He also notes that this reason is used as a rationalisation by a father who must spend long hours away from home, when the covert reason may be that life with his family is not tolerable. He points out that the father prefers, therefore to be away and to leave the responsibility of the disabled child to the wife. The limited attendance of men at the rehabilitation session of their children in this study supports this suggestion, particularly as their partners were also employed, but had managed to take time off to bring their children for rehabilitation. Also the limited number of Black fathers (n =

1) who brought their disabled children for their therapy session supports the African custom that males are considered as the breadwinners while females are expected to do the housekeeping and other caring jobs. A good example of this is that of the men from other Southern African countries who leave their children with their spouses in their home countries or rural areas to come and work in the South African mines. A similar belief in the same custom was evident in the study done by Amosun et al in 1996 on caregivers of handicapped children in Nigeria.

There were also aunts and grandparents who brought the disabled children for their therapy. This suggests that generally the three cultural groups believe in family support to the children with disability and their parents. This is supported by the literature, which says that support, especially child minding, provided by the extended family is important (Beresford, Lawton, 1993). The importance of support of the caregivers is stressed by Venters (1981) who asserts that this support is an important factor in helping families to cope with the task of care giving. The literature emphasises that support by a spouse is the most important (Peterson, 1987, Byrne, Cunningham & Slopper, 1988). An important resource for the mothers is just knowing that this support, if needed, will be forthcoming (Beresford, 1994).

The literature also reveals that maternal grandmothers appear to be more supportive than the paternal parents (Gallagher, Beckman & Cross, 1983). This supports the findings of the current study as most of the single mothers were accompanied by their own mothers, and in the absence of the mother, the disabled child was brought for rehabilitation by the maternal grandparents. This could also suggest that the maternal grandparents may feel obliged to give support as a substitute for a spouse where there are unmarried daughters.

5.2.4 Religion, number of children and marriage.

In terms of their religious affiliation, the results showed that there was some diversity in the three cultural groups. Moslems were found only in the Coloured group while the majority of the three groups said they were Christians. It was surprising to find that the majority of the families of disabled children from the Christian and Islamic

background had two children or less. I had anticipated that Moslems and some Christians would have had more children due to their religious beliefs (in particular, their objections to family planning methods, such as, using contraceptives and abortion). Perhaps, they use other methods of contraception like abstaining. It is also possible that after giving birth to a disabled child, couples may be afraid of having another disabled child.

It was expected and reasonable to find a limited number of children among the Blacks because the vast majority of them were unmarried mothers. A single child to a mother in this group might have been the result of an indigenous experiment to check if that individual is productive before she could be engaged to marriage as most cultures in Africa believes that the prime reason for getting married is to reproduce children. In some African states, infertility is one of the permissible reasons for polygamy and it is also grounds for divorce, so that testing for fertility prior to marriage is important among some indigenous groups. Unexpectedly, there were only a few black mothers (n = 5) who were married in this study. In the African culture marriage is a source of pride to the female family, and more importantly is a way of enriching the family through *lobola*. Families who have female children are seen or perceived to have a potential of wealth. Marriage is also regarded as a means of retaining the family, clan, traditional beliefs and practices.

Perhaps, the majority of the unmarried mothers among the Blacks were undertaking the experimental process prior to their marriage with the expectation of having more when they are married. The assumption is that it would have been unreasonable for that group of mothers to have more children while awaiting marriage. Among the Coloureds and the Whites the reason for having only one or two children may be that most of them were still young, and they may have just married and the intention was to have more children later on. Alternatively some may be using family planning methods.

PART II

5.3 DEMOGRAPHIC DATA OF THE DISABLED CHILDREN

The demographic data of the disabled children will cover age and gender

5.3.1 Age and Gender

The results showed that there were more disabled male children than females. Furthermore there were very few children between the ages of 9 and 13 years. One possible reason for the absence of older children may be that they had already been discharged. Another reason may be that transporting older children to the area of services is problematic. Transport is one of the top needs that caregivers highlighted in their responses.

PART III

5.4 KNOWLEDGE, ATTITUDES AND BELIEFS

5.4.1 INTRODUCTION

In this section I will discuss the levels of knowledge, as well as the attitudes and beliefs shown towards disability by the three cultural groups. The three aspects will be discussed separately according their categories.

5.4.2 SUMMARY OF THE MAIN FINDINGS

The overall score of the quantitative data showed that the three cultural groups were equally knowledgeable about disability. The means were all less than the cut off point of 12.

However, the qualitative data showed that there were some differences in their knowledge. Similarly, the quantitative data on the attitudes towards disability showed that the three cultural groups shared positive as well as negative attitudes in some of the following items: rehabilitation, education, stigma, child bearing, employment, and marriage. The qualitative data, however, showed that there were more misconceptions among the Coloureds and the Blacks in comparison with the Whites.

On beliefs the results showed that there were significant differences between the Blacks and the other groups on the aspect of witchcraft and consultation of spiritual and traditional healers.

5.5 KNOWLEDGE

According to the quantitative data, all three cultural groups had heard or read about disability. To confirm their knowledge on disability the results showed that respondents in each cultural group have a specific name for disability in their own home language. For example, in Afrikaans disability is called *"gestremdheid,"* Xhosa it's called *"ukhubazeko"* or *"isidalwa"*, and in Sotho it is called *"bokuoa"*. The results also showed that the majority in each of the three cultural groups had read or heard about disability. They further showed that all the groups had seen disabled people in their communities, institutions and in their own families. It is, therefore, assumed that all the cultural groups have an idea of what disability is.

A similar number of Coloureds and Whites showed that they already knew about disability when young, while the Blacks appeared to only have known about it after the birth of the disabled child. The results showed that the majority of the Black children had cerebral palsy. This finding is similar to what Molteno (2001) said in his Conference paper on the aetiology of intellectual disability and its implication for prevention. He said that perinatal and postnatally acquired cases were more common in African children than in the other ethnic groups.

From the literature and from the fact that their parents/caregivers only knew about disability after the birth of the child, while the other two groups had information about disability at the early stage of their life, one could firstly conclude that inaccessibility and delayed dissemination of information has contributed to poor preventive causes of cerebral palsy. It is also possible that the service planners and providers siphoned the services and manpower to certain areas, with the Blacks being most affected by the disproportional dissemination of health professionals and their services. This is a possible explanation for why the majority (n= 16) of the black children had cerebral palsy and most of them ware totally disabled (totally dependent).

In addition, it is possible that their living conditions, lack of or delayed health education may have promoted the preventable causes of cerebral palsy, for example, home delivery of mothers at risk. Many of them live in the squatter areas (informal settlements) where overcrowding, unemployment and poverty are rife (Thompson et al.,1993). Here mothers are more likely to have home deliveries (Coetzee, 1990; Rees, 1989) and less likely to attend services for antenatal or postnatal care (Coetzee et al, 1990). If the mothers had attended prenatal and postnatal clinics and delivered in hospital, the risk factor could have been dealt with by means of medical procedures (such as, induction or caesarean section in case of foetal distress).

Thirdly, in some cases home deliveries are conducted because the mother is not able to access appropriate health services or is unable to reach the area of services at the time of labour, due to lack of transport or communication facilities, such as the telephone. It is important to acknowledge that in informal settlements there are very few qualified midwifery attendants or ambulance services. These are some of the difficulties that may have promoted a high incidence of cerebral palsy among the blacks.

What is generally indicated by the data is that there is maldistribution of primary, secondary and tertiary prevention (PHC). The assumption that there is the possibility that the Black mothers may have not been informed about prenatal, perinatal and postnatal risk factors, such as, smoking and drinking during pregnancy, malnutrition, and infectious diseases, for example, tuberculosis and meningitis which could be the source of their children's disability is supported by the results. The results show that only a few Blacks knew about disability and the majority of those only gained that knowledge after the birth of their disabled children. Furthermore, the results show that the Black cultural group knew only four causes of disability, while their counterparts in the other groups knew more causes. Many of the predisposing causes of disability could have been prevented through primary health care and health promotion. Molteno (2001) stressed that the key point to prevention of

disability is to know the causes. He points out:

> Most important perhaps is the fact that determining of aetiology is the first step towards prevention. Knowledge of the aetiology does not automatically imply a preventive measure, but without knowing the cause, no form of prevention can be considered. .... The study of preschool intellectually disabled with IQ's < 50 revealed that 40% could be considered as having been preventable, 16% with existing knowledge and current practice.

The most important prevention perspective was embodied in the WHO commitment in its main theme "Health for all by the year 2000". To follow up on that commitment the South African Government formulated the National Health Plan in 1986 based on the Alma–Ata principle. This was initially planned for implementation in partnership between the state and the private sectors (Dennill et al., 1995). The South African National Health Service Delivery Plan was described in 1991 as an intention to provide affordable, accessible community oriented and participatory primary health care. It was noted by the RDP (1994) that the health policies of the new South African Government required the country to adopt the PHC approach in order to meet the needs of the whole population. The assumption that there is a maldistribution of PHC services is supported by Dennill et al. (1995) who point out that despite the attempt of the Government in attaining some of the goals of the plan, lack of available information and identification of needs, resulted in inefficient planning of the health system. Slabbert (1992) observed that South Africa has the manpower to develop an acceptable health services although certain problem need to be addressed quickly such as (i) geographic mal-distribution (ii) inappropriate training, and (iii) inappropriate utilisation of the different categories of manpower.

Most of the participants from the Black group were from the densely populated informal settlements, which are most affected by maldistribution of manpower. Kolobe (1995) stated that the South African population growth rate by far outpaces growth in the number of health professionals. The children in informal settlements are less likely to be immunised (Coetzee et al., 1990) and are often also malnourished (Coetzee, 1991). Mothers are more likely to have home deliveries

(Coetzee, 1990; Rees, 1988) and less likely to attend for antenatal or postnatal care (Coetzee, 1990). These factors suggest that the children who live in the informal settlements are much more susceptible to infectious diseases, which often lead to disabilities. Violence, poverty, hunger, epidemics, overcrowding, unhealthy housing and living conditions have been observed to be predisposing causes of disabilities (Discussion Paper, 1995). This reinforces the fact that the children who live in informal settlements are more at risk of becoming disabled. This may also be the reason why a large number of children from the Black cultural group presented with cerebral palsy.

Unexpectedly, it was found that the answers given by the Coloured cultural group on the causes of disability covered the complete causal chain of disability, that is, predisposing risk factors intrinsic to the child (for example, prematurity); predisposing risk factors extrinsic to the child (for example, parental drug use); physical/mental impairment with biological aetiology (for example, genetic); manifestation of developmental delay/disablement in the child; and manifestation of sequelae/complications in the child. Examples of that knowledge is expressed in the following quotations:

"The child can be affected if you drink and smoke when you are pregnant. That is very dangerous man, because the child can be born with any type of disability."

".....if the child is a premature the brain can get affected like Michael and he can have cerebral palsy."

"It is our fault. ... if you don't take the child to the clinic for injections she can get sicknesses like polio or these funny measles."

"Many disabilities are caused by accidents. Many of the disabled people in South Africa were involved in the road accidents. You watch your TV tonight you will see."

"You can get disability by inheriting it from your family. It can be either from your mother, your father or your grandparents."

"If the child get infected when she is in you by meningitis, the doctor says it is very dangerous and causes damage to the brain. The child will never be

normal again."

This makes one conclude that because they knew the causal chain of disability they were able to eliminate some of the factors which are preventable such as stopping drinking and smoking during pregnancy, eating healthily and taking their children for immunization.

5.6 ATTITUDES

5.6.1 Introduction

The results showed some misconceptions in the qualitative data on the following items: rehabilitation, education, stigma, child bearing, employment, marriage and social integration as discussed below.

5.6.2 Rehabilitation

All the groups were positive about bringing their disabled children for rehabilitation, but disparity was found in the qualitative data. Rehabilitation is seen as a principal need in all three cultural groups, but the results revealed that the major problem among the Blacks was how to bring the children to the service providers. The Black cultural group showed that they could only bring the children for rehabilitation when they have money because transport was too expensive. They mentioned that it was also difficult for them to travel to the service providers in bad weather and also difficult to carry the children with their assistive devices on public transport. Such difficulties were expressed as follows:

"The taxi drivers don't want the wheelchairs in their taxis. They charge you for the wheelchair, the child and yourself because you occupy three spaces. And sometimes they drop you far from the hospital when it is raining."

" ……my baby gets sick because I walked a long distance to the taxi rank and I also waited for very long time in the rain for the taxi. I also wait for a long time here."

When they were asked what they would do for disabled children if when they woke up in the morning and found themselves the president of South Africa, a majority of them said that they would provide transport so that they would be able to transport their children to hospitals, schools and take them for outings. The transport issue

was also supported by the majority of the Coloureds. They also expressed their desperation on transporting their disabled children to hospitals. Example of what they said:

"Joo! Joo! Sana I can buy every disabled persons a car and get them drivers who will drive them to hospitals, schools and take them every where they want to go like Waterfront."

"I can buy beautiful busses, only for disabled children to take them to the doctor. I can also give them money for petrol."

"I can punish all the taxi drivers and bus drivers for refusing to take disabled people. ... The taxis can only be allowed to take people after the disabled people have finished travelling in the morning like they make them wait for other people to travel first."

"Man! I can get engineers to design special busses and cars for them so that they could come to hospital comfortably."

On the same issue of transport, some respondents showed that they would provide transport for service providers to make things easier in the treatment of their children. They expressed themselves as follows:

"I would give the nurses and doctors cars to go and check all the disabled people in their homes."

"I can build a big hospital in Khayelitsha for disabled people and get the doctors cars to check them every day."

" ..... I would get more therapists, nurses and doctors to give treatment to every disabled person who is not able to come to hospital and provide them with transport. That's what is done in England."

This strongly suggests that it is imperative to bring the services to the recipients. The starting point is shifting from a medical model of rehabilitation to a community -based rehabilitation (CBR) model, and central to that approach is to assess the primary needs of the recipients and the recipient's family, as well as those of the community.

The concept of CBR is supported by Simeonsson's (1991) study where the aim was to present a comprehensive framework for the provision of child and family services

by conceptualising early intervention in terms of level of prevention. He strongly asserts that primary, secondary and tertiary prevention can be implemented in the context of CBR. The focus should be in the community, with the service best delivered not in large and possibly remote to institutions, but closer to the patient and his family, often in his home (Aitken & Walder, 1987). They also point out that the careful distinction of impairment, disability and handicap marks the transition from emphasis on treatment in hospital to what is necessary in the community to help society discharge its acknowledged duty. They further argue that what doctors and therapists do for the patient is then seen in the related context of what any carer and the disabled person himself can do to improve his situation. This stresses that family and community integration is imperative in the rehabilitation of disabled people in order to achieve appropriate attitudes toward disability and people with disability.

Wade (1996) emphasises that one aim of rehabilitation is to reduce handicap, not disability, to the minimal level, and that is achieved by making the most of the individual's behavioural repertoire, and environment, and by helping to reduce the emotional distress experienced by the patient and his family. Institutional rehabilitation (bringing the client for interval or daily sessions to the service providers) is a complex crux which will take decades to complete, especially when dealing with the less privileged in the developing countries. The model exposes the individual to unnecessary travelling, sometimes with a set of assistive devices, and to the hazards of changing public transport twice or three times before getting to the area of service. Worst of all, it introduces the individual to new people in a new environment that costs the individual much in terms of energy, effort and a long period of adapting to the whole package. The option of simplifying the whole puzzle is to bring service to the recipient in a familiar environment and culture, in his home and his community.

The fundamental principle of CBR is to provide primary care and rehabilitative assistance to disabled people by using the human and other resources already available in their community (Mitchell et al., 1993). Including the existing social and

community infrastructure gives ownership to the community members. That feeling of ownership may encourage them to co-operate and participate in the programme.

Negative attitudes are often expressed in terms of exclusion from various aspects of life (Mitchell et al., 1993). To reinforce the inclusion of community is important in the change of attitude towards disabled people. Mitchell says that requirement of WHO for CBR programmes is setting rehabilitation in the community and giving the community the responsibility for conducting rehabilitation programmes. Their evaluation done in the People's Republic of China, found that CBR does change attitudes towards disabled people. It revealed that communities in which CBR is being carried out develop more favourable attitudes towards people with disabilities than do those in which no such programme has been implemented.

5.6.3 Education

All the respondents across the three cultural groups hold positive attitudes on disabled children attending school. All the groups agreed that it is their right to learn and be given education of any form. The findings showed that Blacks and Coloureds reported that although education is a need and is good for disabled children, the children should have their own special schools because in the mainstream schools they are not taken care of and the disabled children are often ill-treated and mocked by the students and teachers. Example of such attitudes from the school children and teachers are expressed by parents in these quotations:

"They are better off in their own schools where they are accepted and respected. ... In the normal schools the other children and teachers mock them and ill treat them badly."

"Teachers don't care about them and other children laugh at them ... I don't want to make my child a poppy."

" ...they call them names and refuse to help when they need help. They say they are stupid."

"It is good when they are in their own school. ...It is very bad in the other schools. When you child comes he is crying and tells you they called him this and that. Those teachers don't care, man, enough is enough."

What is suggested here is that there is lack of disability awareness among school children and teachers. It is clear that the integration of disabled children into mainstream schools is currently not possible. Without disability awareness integration remains problematic because integration is not merely placing the disabled children in the school building and bidding them 'goodbye'. It means full orientation towards disability, co-operation, commitment and devotion of both the school children, teachers, families of disabled children, professionals and the entire community. Integration prior to disability awareness is like throwing a coconut to a child to crack. To the child that coconut may mean a ball to toss and kick around, not knowing that it is food and the shell could be used as a bowl for his food. Informing him about the benefit of having that coconut, will help him to appreciate and respect it. Maybe the easiest way to implement integration would be to follow what is being done by NGOs, like the SACLA Health Project.

The project targets schools where disability awareness is lacking. The disabled people with the assistance of Rehabilitation workers and the professionals raise awareness by using a form of art (drama). This gives the teachers and the children the opportunity to ask questions and get a better understanding of disability, how it can occur and how the people with disability feel, their needs and rights.

Another problem underlying the integration of the disabled children into mainstream schools is the structuring of the school buildings. To date the vast majority of the public and school buildings still have stairs which pose a problem for people with disabilities, yet the main on-going topic is decentralisation and integration of disabled people to the society, as well as inclusion of children with disability in the mainstream schools. This problem was highlighted by some respondents in response to Question 36. They mentioned the difficulty of accessing school buildings and many public buildings. Examples of how such difficulties were expressed are in these quotes:

"I would build the schools with lifts and big toilets which will allow the children to get in with their wheelchairs."

"I can scrap all the buildings without lifts and build the new ones with lifts and

intercoms."

"...I would build churches, halls, banks, school, hotels and everything with ramps and lifts and also have guards to help disabled people."

The restructuring and planning of buildings to allow access by disabled people is a vital yet neglected component of integration. Inappropriate planning leads to the increased uncertainity of successfully integrating disabled children. This sad reality is very frustrating for the disabled and their carers.

Appropriate planning and restructuring of public buildings in many third world countries is lagging on all fronts and appear incapable of taking off. A good example of this are the taxi and the bus ranks. Children with disabilities are expected to board buses and taxis to school yet there are no suitable structures to help them do this. The whole issue of integration can be compared to a guest of honour invited for dinner where the host puts all the food inside the wine bottle and then expects the guest to access the food in the bottle with his bare hands, all the while knowing that the food is not mend for him but, for those who have gadgets to get the food out of the bottle. Simply put, it is rather difficult for the disabled children to access the main stream school without proper preparation and structures. To make a departure from the current frustrating situation will require effort and dedication from all communities and the obvious involvement of disabled people in governments' strategic planning, otherwise the whole process will be seen as mere window dressing.

This research explains why up to now it has been difficult to integrate disabled children into normal schools and why there are so many special schools for children with disabilities which accommodate those who could possibly manage in mainstream schools. Very often where there is a lack of knowledge, attitudes become negative. Incorrect information leads to wrong assumptions and judgements which in turn produce inappropriate attitudes.

Bakheit and Shanmugalingam (1997) assert that the study of the attitudes of society towards disability is useful for effective targeting of educational and other

programmes that aim to promote positive attitudes and reduce prejudice. Their study revealed that young people showed positive attitude towards disabled people. In contrast, the results of my study show that the younger people (school children) among the Coloureds and Blacks still hold negative attitudes towards disabled people. The findings indicate that the attitude of the caregivers is that educational programmes are important to disabled children but that the major problem is lack of inclusion of the disabled children in mainstream schools because of the attitude of the school children and teachers.

Previous studies have also shown that community attitudes toward the disabled are generally negative. The discrepancy between this study and the Bakheit and Shanmugalingam study may be the result of the use of different methodologies possibly from quantitative data alone. The use of qualitative data in attitudes research is highly recommended by Söder (1990). This author asserts that the method which is used in attitude studies is inefficient and the interpretation of it is unsatisfactory. Söder (1990) writes:

> My critique will be developed along two lines of argument. The first one is of a methodological nature. I will argue the mainstream of attitude research is based on a simplified conception of attitudes and an accompanying simplistic methodological approach. Moreover, I will argue, that some of the methods used create the kind of categorisation that is then taken as an indicator of prejudice. My second argument is based on an interpretation of the results of research. Even considering the limitations in the theory and methods, some conclusions can nonetheless be drawn about the content or attitudes toward persons with disability. I will suggest an interpretation in terms of ambivalence instead of prejudice.

The type of studies in the field of disability that are best suited for capturing ambivalence at an individual level are qualitative studies, aiming at analysing daily social interaction (for example, Bogdan &Taylor, 1987; Goode, 1979, Schneider,1988).

5.6.4 Stigma

The results for this item show that Blacks felt that disabled people were different from other people, besides just having difficulties with physical activities. They queried the thinking and understanding of the disabled people. This group believed that disabled people did not understand and think like other people. Here is an example of this:

"Sisi, they don't understand like us. When you talk to them they understand nothing. ... Even when he grows up Mfengu cannot go to school. It is difficult for him to think and understand. His younger sister understands better in everything."

However, the responses can be linked with the demographic data that shows that this group also have more cerebral palsied children with profound disability compared with the two other groups. According to this data, it is justified for this group to believe this because the majority of them are dealing with intellectual disabilities as well as physical disabilities, so they may assume that disability is always linked with problems of understanding and thinking. This same group had only known about disability since the birth of their child and in the knowledge section of the questionnaire the majority of them only gave causes that were specific to their own child's condition.

This result (believing that the disabled are different mentally) may too have come about partly as a result of indigenous understanding of disability since this group showed very limited knowledge of the causes of disability. Saying that people with disability are different from other people should not, however, be regarded as a way of stigmatising disabled people, because the results showed that the same people were not afraid of disabled people nor did they think that they were inferior.

Oliver (1990) in Imrie, 1997, refers to the personal tragedy theory of disability or the concept which sees disability as something which is wholly a problem of and for the individual. Imrie (1997) said that as a result the discourses on disability have tended to blame the victim who, he says, portrays people with disability as inferior,

dependent, and by implication, of little value or no value. One would expect that since the Black cultural group queries the thinking and understanding of disabled people they might also consider them inferior. Surprisingly, though, both the qualitative and quantitative data showed that like the other cultural groups the Black group did not consider disabled people inferior, neither did they show fear or pity towards people with disability. It is possible that, as the majority of the respondents in the three cultural groups were Christians, they looked at the disabled from a Christian viewpoint, which says, "In the eyes of God we are the same".

5.6.5 Marriage

It is interesting to find that the Blacks considered marriage for disabled people a right while, the Coloureds and the Whites regarded it as way of enjoying life. The results showed that the parents from the Black group wanted their children to marry so that the spouse could take care of the partner (the disabled partner). They expressed the African belief in which the female is expected to do the care giving role and the male is the breadwinner and must provide for the wife and the children. They expressed themselves as follows:

"I will be very happy if she can get married. ... The husband will be able to take care of her and take her to the doctors and her children will also take care of her."

"At least if he is married I know there is some who will cook, wash and take care of their children and the family."

This notion was identified in the study done in Nigeria by Amuson et al (1996), which identified that care giving was considered the role of women. This may be the reason why there were very few Black men who brought their children for rehabilitation.

The parents also regarded marriage as security. They expressed that when the female is married she has protection and financial resources, as well as emotional support, all of which must be provided by the parents if she remains unmarried. In contrast, the findings showed that the Coloureds and the Whites found marriage as

a way of enjoying life with the other person. Example:

"Yes they should. ...love knows no monster. If they love each other let them enjoy life."

"They are human beings, they have feelings. If they have found love let them enjoy themselves. We live once."

What is being suggested here is that to the Blacks marriage is a total shift of responsibility from the female's family to the male and his family, while the other two groups regard marriage as a way of enjoying life with another person.

5.6.6 Child bearing

The three cultural groups similarly accepted that disabled people could have children. Whites and a majority of Coloureds added the condition that the disabled people should get medical advice prior to having children. This was expressed this way:

"It is their choice, my dear. ..... but it is better if they could see the doctors before having the baby. ...life could be nasty if they can have a disabled child too."

"If they wish so why not? I think if two people love each other and want the children it is good, but I think they have to go for a check up before having a child because if you are disabled you can also have a disabled child."

This is an indicator of clear understanding that disability may be inherited. Hereditary factors were given as a cause of disability by a few respondents from these two groups. This also confirmed that even those who did not mention it under the causes knew that it is a possible cause of disability.

The results showed that to the Black cultural group for a person with disability to have children is considered as a family schema, a way of increasing the individual's caregivers, security and mutual support. Some mother expressed it this way:

"Sana, it is difficult when you don't have the husband. I have seen some people with his problems who are married and have children. Their children are taking care of them. My next-door neighbour is the same. The children are doing everything for him. He does not have worries, sisi."

"It will be very good if she can have children, they will take care of her and give her money when they are working."

A family schema which is highly resistant to change could include values such as respecting and maintaining one's ethnic heritage and honouring and respecting one's elders and sharing an unwavering commitment to the care of children and commitment to preservation of the family unit (McCubbin et al., 1993). The impression here is that care offered by children seems to be valued and very meaningful to this group. Children are expected to render care to their parents, especially financial and physical care.

In the Western population it is a norm or tradition to take parents to an old age home as soon as they are not capable of taking care of themselves, where care is provided by employed caregivers. In contrast, among the African ethnic groups sending a parent to a home is regarded as a disgrace and disrespectful towards the person (ubuntu). The traditional expectation is that children are to take care of their elders. Having children is also seen as a way of extending one's family and clan which is why among African it is important to have children, especially male children who will carry the family name and pass it on to the next generation. What the results indicate thus links with what has been observed by McCubbin et al. (1993). They point out:

> Historically, the family has been the conduit for cultural transmission, proving a natural atmosphere for tradition to be passed from generation to generation, as well as updated throughout the ages to keep culture and ethnic heritage alive. In turn, the traditions themselves have given families a sense of stability and support from which they draw comfort, guidance, and a means of coping with problems of daily life.

5.6.7 Employment

There is evidence that in the developed countries attitudes toward people with disability are becoming less negative (Westbrook et al., 1993). In contrast, current belief is that discrimination against the disabled is common in the developing

countries (Chermak, 1991; Kopparty, 1994). However, unexpectedly, the findings of the present study showed that even in the developing countries attitudes towards disabled people have shifted from negative to positive. The majority of the respondents from the three cultural groups were in favour of the employment and promotion of disabled people. For instance some respondents affirmed their belief in employment for disabled this way:

"Why not? They are looking for jobs like other people because their grant is very little. ..if not badly disabled they should be given the job. They are very good. Some are cleverer than normal people."

"I would definitely employ them. ...they can also do good job. ... apart from that they also need some income."

" If the person is competent promote him. ...I have seen a lot of them in many companies doing a good job."

The responses are in line with the Disability Rights Charter of South Africa, which stresses that disabled people have a right to employment in the open labour market. These findings are also in accord with the study of Bakheit and Shanmungalingan (1997), which showed that the vast majority of the members of the Asian community expressed acceptance of disabled people and acknowledged their rights for vocational opportunities. This suggests that even among the ethnic groups attitudes towards vocational opportunities is relatively positive.

5.7 BELIEFS

5.7.1 Beliefs in God

Culture influences our beliefs in many ways. It influences our beliefs in other things such as causes of illness or disability, and what a person does when she/he is ill or disabled is another cultural artefact (Banja,1996). The results of the current study, showed that some respondents among the three cultural groups who a majority (N = 51) were mainly Christians, some of them believed that disability is from God. There were some discrepancies in that belief. Some respondents had the positive belief that disability is a gift and a blessing from God while some believed that it is a curse or a punishment. Example of positive beliefs are expressed in the following

quotations:

"....God gives you this type of the child because he loves you and trust you." " God can not give His children bad things ...He presented us with this precious angel to show His love to us."

"Joan is a blessing to our family ... without her we feel empty. When she was here (Red Cross Hospital) we felt lost. We could not stop praying."

These responses are in accordance with medieval Christians' belief that viewed the disabled as being in possession of special gifts bestowed by grace of God (Cusack, 1997). Among the Mexican American and African American children with disabilities are also considered as gifts from God (Kalyanpur, 1999). The American Mexican also believe that if disability occurs, they are singled out by God for the role of their past kindness to a relative or neighbour who was disabled (Groce & Zola, 1993). It can arguably be assumed that a positive attitude towards a problem or a bad experience creates an inner awareness of wholeness. The awareness of wholeness is clearly related by Burns (1989) in Do Rozario (1997). They state:

> This experience of wholeness or consciousness extends and challenges the view of disability and illness as only a meaning - making and revaluing opportunity in the life of people. Instead, the model of wholeness and reconstitution points to the possibility of an implicate order of consciousness of wholeness in which people who have undergone some crisis or critical incident in their lives may be able to access and express 'deeper reality ' or flow in life.

Having this awareness of wholeness may help the believers to cope better with the disability and its consequences. A good example of this is found in Elliot's (1997) study where the respondents - the wife of clergyman who developed Alzheimer's disease - reported that she and her husband always believed that whenever there was a trouble Jesus would come and touch people on the cheek and they felt that the Lord was always with the husband. As a result of keeping that strong faith very little aggression was shown by the husband when he contracted Alzheimer's disease.

In contrast some respondents said disability is from God but they viewed it in a negative way. They believed that disability is a curse or punishment from God. An example of such beliefs include the following quotations:

"I think it's the punishment from God. You know, my other son is like this too. .....It is very difficult for us."

".... Sometimes God put us in difficult tests. Why do I have this type of children? This is a very big punishment from God. My husband left us. It is five years now."

The responses are in accordance with Leavitt (1992) who observed that disability can be considered as a curse from God for the sins of the family or individual or as a result of invasion of evil spirit. The possibility may be that the people who have a negative belief about disability may experience the emptiness because they believe they have sinned against God. They may fail to cope with the disability or caring for those who are affected by it because they already view it as a burden. There were also a few respondents who believed that disability is from the devil, not from God. They expressed it as follows:

"The devil always plays his tricks, but Allah (who they explain as God) is always good and protect us from him."

"God cannot give his children disability. Disability is the work of the devil."

"All the bad things like disability are from the devil."

Surprisingly those who claimed that disability is from the devil sounded positive and strongly believe that with help of God and professionals their children will improve. They also claimed that they will rely mostly on God while they are seeing medical professionals. Some respondents reported that they would also consult religious healers to pray and prophesy over their children. They expressed themselves as follows:

"..sometimes God listens to us. Let me tell you they prayed for him and after that he improved very much. He can now stand up."

" ...when they prayed for him he became better. He stopped [having fits]."

"Ever since we started putting our faith in God's hands he started getting better and better. He is no more having those bad jerks."

5.7.2 Beliefs about witchcraft and spirits

Overall, the lay theory of illness and disability regards the causes of disability as witchcraft spiritual and supernatural causes (Ngubane, 1977; Locust, 1988; Jackson & Mupedziswa, 1988; Hammond-Tooke, 1989; Mayers, 1992; Higgins, 1992; Groce, 1993; Devlieger, 1995; Drews et al., 1996; Ingsted, 1998), The results of the current study supports these observations. They show that some participants in the Black cultural group blamed disability on witchcraft spiritual and supernatural causes. Here is an example of the comments of some of the mothers who believed that disability is caused by witchcraft:

"Because my husband chose to marry me instead of their daughter, they decided to make me barren. I have only this one child who they also bewitched. He cannot talk or walk. He does nothing."

"... they get jealous of you and your family and they bring medicine to your children. My son was well until when we went to Transkei and he just got sick after that, he could not walk or talk any more. They said the medicine is in the bone marrow."

"Some people get jealous of your family and send you medicine. Because the boy is young it goes to him."

The results of this study are similar to the findings of the previous studies done in Zimbabwe by Jackson et al. (1988) and by Drews et al. 1998 in the Northern Nyanka District of Zimbabwe. Their studies showed that disability is blamed on witchcraft, ancestral spirits, God and natural causes. The findings of Jackson et al. (1988) also revealed that there was an equal likelihood among both Christians and non-Christians of ascribing disability to witchcraft. Similarly, the current study showed that the vast majority of the Blacks were Christians, yet some of them firmly believed in witchcraft and said they would rely on professional health services as well as traditional healers for help. They expressed themselves as follows:

"It is good to take him to the *ugqira* (traditional healer) too because he tells you who has done this to your child."

" .....at hospital they are good because they exercise the child but you never

know who has made your child like this. So your child is still in danger if you don't know the person."

According to the results of the present study some black respondents believed in the health professional services, God, witchcraft and traditional healers. These surprising mixed-up beliefs are common among the indigenous groups. The same beliefs were found among the Tswana in the study done by Ingstad (1998). The study results showed that although majority of the Tswana would choose modern health facilities they still had quite a strong trust in the folk healer. As a result those who had given the medical health services as their first choice quite often gave the consultation of folk healers as a second choice.

Ill behaviour is a normative experience governed by cultural rules (Kleinman et al, 1978) and so is disability. It is shaped by cultural factors governing perception, labelling, explanation, and valuation of the discomforting experience (Fabrega, 1972). Medical anthropologic studies confirm that folk healers in the developing societies are interested in treating illness (Kleinman, 1975). Zola (1972) states that the healers seek to provide a meaningful explanation for illness and to respond to personal, family and community issues surrounding illness. The responses given by the Black cultural group strongly suggest that what the client needs is an explanation that is meaningful and in line with his/her culture, which meets his/her expectations created or shaped by that culture. Even if they have chosen to consult the medical health facilities initially, its failure to provide a meaningful explanation diverts them to the folk healers and sometimes makes them abandon medical facilities completely. It is clearly indicative that for some Black respondents consulting both health professional services and folk healers is satisfactory, as their expectations are met by the folk healers who always tells them the source of the problem and the means of solving that problem. The example of how the problem is explained and solved is expressed in this quotation:

"They say I sucked it from my mother and Sisiphiwe got it from me. ... We will go to Trankei when my mother gets money to slaughter the cow. I don't like to have another one like her."

"They put the medicine for me when I was pregnant .My body was full of that

medicine and it passed to my child. That medicine has blocked my womb I cannot have children again."

The importance of knowing the source of the problem among the native groups was also found in Drew's (1996) study. The findings showed that among the Shona tribe in Zimbabwe the cause of illness was blamed on witchcraft and when an individual is ill the folk healer is consulted to find out the cause of the illness and the healer gives or prescribes an appropriate medicine to overcome the spiritual power which has caused the illness.

Obviously the critical point is reached when the culturally patterned treatment expectations are met by the folk healer. Therefore, there is no big deal in going for a 'fix' (rehabilitation) provided by the health service providers. Perhaps the reason for going for a 'fix' is to satisfy the peers, the civilized society around the client and the nagging professionals who always want the client to understand their medical perception of illness and disability model of treatment regardless of the client's subjective meaning to his/her illness or disability. In many cases, because their needs are neglected and are overpowered by those of the service providers, some clients default or abandon rehabilitation completely.

The majority of the black respondents, when asked if they would bring their children for rehabilitation, answered positively. Surprisingly when they were asked why they would do so, some of them gave the following reasons.

"……the doctor wants him to come to hospital."

"The nurse said I should take him to hospital because it is good when we come to the exercise place at least once a month."

"My sister said it is good for me and my child because I will get a nice pram like the teacher's wife."

Initially, these responses make one think that the clients feel that attendance is expected of them by the medical professionals, or that they have nothing better to do. They also give an impression that the client has come for rehabilitation without a purpose or goal, but to impress the people around him/her. It is possible that these

are clients who as a rule or habit consult folk healers first and are satisfied with the folk healers service, but come for rehabilitation to satisfy others who have shown concern about the modern medical facilities. Inattention to the client's culturally patterned treatment expectations puts the patient out of medical health care. This may, in turn, prevent him/her from receiving a relatively specific therapeutic agent (Kleinman et al,1978). However, consulting the two – the health professionals and the folk healers could be rewarding and satisfactory to the client as the health professional service may only be consulted to maintain the status quo around the client, while the latter fulfils his culturally patterned treatment expectations. This practice of consulting both the health professionals and the other healers was also revealed in a study reported by Kleinman (1975). The findings showed that the Taiwanese clients were satisfied by consulting the Western doctors for the reason of getting injections, the Chinese doctor to get the prescribed herbs and answers to his questions, and the folk practitioner to receive more attention.

5.7.3 The effects of the beliefs

These views on the causes of disability and its treatment are common around the globe among indigenous groups. In a number of African, Caribbean and Paciffic Basin societies as well as among native Americans, witchcraft is strongly associated with ill health and close association with such people is believed to place others at risk for witchcraft (Groce, 1993). What is suggested by the results here and the literature is that these beliefs foster negative attitudes towards disability and make early detection, intervention and rehabilitation of less likely.

Firstly, it can be argued that such beliefs may hamper the co-operation and participation of the community members, extended relatives and mainly the member of the family in rehabilitation process. French (1994) asserts that our beliefs and values constitute our attitudes, which may in turn affect our behaviour. Similarly, our decisions are governed by our beliefs. Basing my reasoning on these statements it may also be argued that early identification and intervention is partly anticipated by attitudes formed by the beliefs about disability.

Secondly, it can be argued that these beliefs perpetuate the hiding of the children and depriving them of early intervention for fear of being stigmatised. Groce (1993) says that where blame is attached to the individual who is disabled, siblings who are of marriageable age are likely to hide the disabled member away in the fear of reducing the possibility of finding a suitable spouse, or parents may do so for fear of loosing their jobs and social status. She further says that it may also be done from the fear of being seen as having been involved in an extramarital relationship, as this could lead to losing the spouse, the family friends and respect from society as a whole.

Thirdly, if people with these beliefs do ever come for rehabilitation, they only come after consulting the folk healers. Meyers (1992) states that the Hmong community in the United States of America would mostly choose traditional medicine before consulting the Western medical services. This practise consumes a lot of time and delays early involvement of the children in the rehabilitation process. This impact is reinforced by Loveday (1993) in her evaluation at the SACLA Rehabilitation Project where her findings showed that the Xhosa mothers in the township of Khayelitsha Cape Town first seek folk healing before they go for medical advice and treatment. This is indeed still in practise to date, for example, among the Swazi, Zulu, Sotho, Xhosa and many other Southern African tribes. When someone is ill the folk healer is first consulted before seeking medical advice. The majority only turn to medical treatment when the folk healers have failed. This is also common among the parents/caregivers of cerebral palsy sufferers. They usually opt for folk healing and then only come for medical advice and treatment and rehabilitation too late when, deformities and other complications start becoming obvious or have taken toll.

Another greater concern is the failure of parents to nurture and provide adequate on-going care, education and emotional support, as a result of numerous reasons, such as, embarrassment about the condition of the child, keeping the child isolated in an effort to protect them from the jeers and taunts of others, as well as the fear of bringing unwanted attention to the family (Groce,1993).

Early intervention is only possible if parent/caregivers come forward for the services. This can be made possible if service providers meet their needs, which so far have been systematically ignored by most professionals. The vessel to that achievement is knowing and understanding the culture, values, beliefs, and expectations of the clients. Illness is shaped by cultural factors governing perception, explanation and valuation of the discomforting experience (Fabrega, 1972). So is disability. A good example of how cultural factors, environment and perception could shape disability is given by Werner (1988). He writes :

> A disabled child who is mentally slow but physically strong, in a village may not be very handicapped, but in a city or school may be very handicapped. A child who is physically disabled but intelligent, in a village may be very handicapped, but in a city or school may be especially handicapped.

The way we communicate the health profession, how we present the symptoms, when and to whom we go for service care and for how long we evaluate service are all affected by cultural beliefs (Klenman, 1975). Simply put, Banja (1996) says rehabilitation starts in the mind, he writes further:

> Probably because we all recognise the key role that a patient's attitude, motivation, and cooperation plays in the rehabilitation process. But if we really examine the meaning of this statement, we have to appreciate the way that social values and cultural beliefs affect the rehabilitation process.

According to Banja (1996), the deeper core of rehabilitation lies in the recipients' beliefs, attitude and perception towards disability. To fully understand the needs of the client, we should acknowledge and relate to their beliefs and perception towards disability, the reasoning being that clients are very quick to attach subjective meanings to their sickness or illness (Banja 1996). Resistance to the medical professional interpretation of disability perpetuates and reinforces negative attitudes in the whole process. To better service children and persons with disability we need to have a good understanding of their cultural beliefs and accommodate them in the rehabilitation process. Service providers who are aware of the cultural beliefs of their

clients are able to make allowances for this and follow their cultural practices while encouraging them to come for the health services. This allows the clients to analyse and gauge where they actually benefit more.

As painful as it is to say, whether it is out of naïveté or sheer ignorance, the truth is that the professionals and specialists believe that they are physically and mentally superior to the client and, as such, should persuade them to accept their medical perception and model of treatment regardless of their own beliefs, values and perception on disability. This view relates very much to an army mentality that says "if you are in power, overrule others regardless of their feelings and needs". To dictate rules, insisting and convincing the clients about the medical perception of disability and its treatment will drive them away from medical services. Operating within their environment, in line with the wave of freedom and respect for their values and culture may manage, however, to earn their confidence in the medical health model perception and services.

More importantly, we should strive to maintain their newly retrieved perceptions by seeing and treating their folk healers as colleagues. For example, in Lesotho the majority of the traditional healers are registered and have their own association. In a lot of cases, they work hand in hand with the health service providers. They are oriented by the service providers on many issues. This uplifts and opens the window for communication between the two systems. It also gives them ownership in the national health system. Many cases like gastroenteritis, (which they call *'Phuoana'*) if the child presents sunken eyes and collapsed fontanels they are referred to the health service providers with immediate effect. This may suggest that the problem is in using the biomedical model on clients from cultural groups and failing to meet their culturally patterned treatment expectations, which is their priority. Attention to their priorities first gives satisfaction and may further facilitate the client's and his family's compliance to the medical health professional services.

Cultural beliefs influence rehabilitation in different ways, some people believe in God, some in the spirits, some in witchcraft and some in biomedical models. This set

of beliefs creates and shapes our perceptions towards disability and its treatment. But, the bottom line is to help people with disability to improve or to enjoy a better quality of life with their disabilities. Sensitivity and respect to each and every belief is the only channel to cooperation that will lead to achieving everybody's goal –a satisfactory REHABILITATION out come. This will also resolve the misunderstanding between the health care professionals and clients when it come to making decision on rehabilitation intervention.

****

CHAPTER 6

LIMITATIONS OF THE STUDY, RECOMENDATIONS AND CONCLUSION

6.1 INTRODUCTIION

In this chapter I present the limitations of the present study, the recommendations arising from the study and my conclusions.

6.2 LIMITATIONS OF THE STUDY

There are two main limitations that influence the generalisation of the findings. Firstly, KAB surveys rely on probability sampling to ensure that the results are representative of population of interest in the study (Katzenellenbogen et al., 1997). Systematic (quasi-random or non random error) methodological sampling is recommended for KAB surveys by Katzenellenbogen et al. (1997). This method is used if a large percentage of the people to be interviewed are not interviewed for certain reasons. In the current study, it was utilised due to the limited number of respondents and time constraints. To gain more insight and to achieve the information needed for the study, the purposive sampling methodology was also used.

The researcher only interviewed the respondents who could understand English and speak it well enough to respond to the questions. The researcher opted for this method due to the lack of funds to employ research assistants who could speak the language(s) of the participants. However, the main reason for opting for the method is because Katzenellenbogen et al. (1997) caution that translation poses further problems when the target language(s) lacks the vocabulary suited to the goals of the questionnaire. It may also be necessary to translate the questionnaire into targeted language and then back-translate it into the former language. This consumes a lot of time and funds and the questionnaire may also end up losing some of its original meaning. Although the respondents were drawn from the referral hospitals that provided access to interviewing the respondents from various regions of the Western Cape Province, because I used non-probability sampling, it is difficult to make

generalisations from the results. This was further compromised by the relatively small group size used of caregivers from the three cultural groups. For these reasons the findings cannot be generalised to the entire country or to other groups.

Secondly, the respondents were interviewed on the hospital premises, which is an unfamiliar environment to them. The researcher is aware that the environment could influence the respondents to hide the information about their cultural beliefs and attitudes because they were surrounded by Western professionals and interviewed on their premises. Furthermore, the interview was conducted in English, a language that is not used regularly by the majority of the respondents. This could also limit the extraction of important information due to the respondents' failure to express themselves well in English.

6.3 RECOMMENDATIONS

These recommendations are based on the findings of the current study.

6.3.1. RECOMMENDATION TO THE HEALTH, EDUCATION, AND LABOUR DEPARTMENTS AND THE NGOS

- As the United Nations have undertaken a commitment at the World Conference on education for all (United Nations,1990) and the Disability Charter of South Africa demands that disabled people should have a right to mainstream education, it is recommended that a larger KAB survey should be done. This survey should use a larger sample size to ensure that the results are more reliable and allow for a generalisation of the results, so that disability awareness can be raised, where necessary, prior to the inclusion of disabled children in mainstream schools.

- It is also recommended that an evaluation be done to compare the schools where awareness has been raised by the NGOs with the other schools where awareness has not been raised. Conducting such an evaluation will inform the department involved in implementing inclusive education as to whether raising disability awareness is a solution to the existing problem of

negative attitudes that are obstructing the integration of disabled children into mainstream schools.

- The existing NGOs should be subsidised and supported by the Government in order to promote and maintain the ongoing CBR services and to create more posts for CBR workers and professionals who will work in the community.

- Bringing rehabilitation services to the recipients is a crucial need. Rehabilitation programmes should change from the medical model to community based rehabilitation (CBR). Most universities training therapists have included CBR in their curriculum. It is recommended that such programmes are evaluated periodically in order to establish whether they are achieving the required results.

- To prevent disability, Health Promotion should be part of curriculum in the primary and high schools, targeting all the youth.

6.3.2 HEALTH PROFESSIONALS

- It is recommended that professionals should be trained to be culture sensitive and to respect the values and beliefs of their clients. It is also recommended that while addressing harmful cultural beliefs which delay the early identification and intervention of children with disability, professionals should be accommodating and sensitive to the caregivers' view of disability and their expectations, otherwise they may feel alienated and default or drop out of the rehabilitation process.

- It is also wise to respect the folk healers and treat them as colleagues as this is a window for communication and dissemination of information on health issues. This, in turn, may help to change the beliefs and attitudes towards issues such as disability and its causes, which influence rehabilitation and its outcome.

6.3.3 GENERAL

- People with disability should be involved in the planning and restructuring of policies.

6.4 CONCLUSION

This study raises some issues in certain key areas on primary health care (PHC). It highlights that there is a geographic maldistribution of information among the there cultural groups and disproportional distribution of services, all of which lead to a higher prevalence of disability in some areas of society.

The lack of, or very limited knowledge on certain health issues, such as disability, in certain areas, prevents the integration of disabled children into mainstream schools.

In future, a bigger KAB survey of this kind should be done to determine the knowledge, attitudes and beliefs towards disability in the schools and communities, in order to implement the inclusion of children with disability in mainstream schools. It is also necessary to raise disability awareness among the school children, the teachers and the community at large, to change the existing negative attitudes as preparation for inclusive education and community-based rehabilitation.

Transport is a very frustrating issue for disabled children and their families. Public transport should be able to accommodate disabled people and the community should be geared to assist where necessary. It is crucial that service providers bring services to the recipients (that is, a shift from the institution-based rehabilitation model to a CBR model). More important, is the need to upgrade CBR programmes in the training institutions (for example, by sending the trainees for Electives/practicals or work experience in the community, mainly in the rural areas where there is more need).

The study also highlights that there are different cultural beliefs towards disability

and its causes, such as witchcraft, ancestral spirits, believing that disability is from God and sometimes the devil. These beliefs delay and hinder the early identification and intervention of disability in children. Early identification and intervention/ rehabilitation programmes are of primary importance for disabled children and their families. In conclusion, it is also crucial to respect the client's culture, values and beliefs and consider their expectations, so that both the recipient and the service provider are able to achieve a satisfactory rehabilitation outcome.

****

REFERENCES:

Aitken C. & Walker J. (1987). *Care of the disabled people in the community. Symposium: Care in the community* (WHO consultation).

Amosun S.L., Benson A.L. & Iyabo J.O. (1996). Rehabilitation of the handicapped children – who cares for the caregivers. *S.A. Journal of Physiotherapy*, 52, 3: 56-59.

Annual Report (1999). Department of Health. South Africa.

Aranda M.P. & Knight B.G. (1997). The influence of ethnicity and culture on the caregivers stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37: 342-354.

Asbury G. (1995). Societal response to myalgic encephalomyelitis: The construction of an attitude measure. Unpublished masters thesis, University of Port Elizabeth.

Babbie E. (1992). *The practice of social research,* 6th ed., Belmont, CA: Wadsworth Publishing.

Bailey K.D. (1987). *Method of social research* (3rd ed.). New York: The Free press.

Bakheit A. & Shanmugalingam V. (1997). A study of attitudes of a rural Indian community toward people with physical disabilities. *Clinical Rehabilitation,* 11: 329-334.

Banja J.D. (1996). Ethics, values, and world culture: the impact on rehabilitation. *Disability and Rehabilitation*, 18: 279-284.

Baron R.A. & Byrne D. (1991). *Social Psychology*. 6th ed. London: Allyn & Bacon.

Bauer D. (1989). Foundation of physical rehabilitation: a management approach (1st ed.). Churchill Livingstone.

Bell J. (1987). *Doing your research project.* Milton Keynes: Open University Press.

Benade M.M., (1992). Distribution of health personnel in the Republic of South Africa with special reference to medical practitioners. *South African Medical Journal*, 82: 250-263.

Beresford B. & Lawton D. (1993). *Coping with the care of a severely disabled child*. Final report to Rowntree Foundation. JRF 1078, Social Policy Research Unit, University of New York.

Beresford B.A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychiatry*, 35, 1: 174-209.

Birenbaum A. (1970). On managing a courtesy stigma. *Journal of Health, Society and Behaviour,* 11: 196-206.

Bogdan R. & Taylor S. (1987). Toward a sociology of acceptance: the other side of the study of deviance. *Social Policy*, 34-39.

Bradshaw D., Dorrington R. E. & Sitas F. (1992). The level of mortality in South African 1985 - what does it tell us about health?. *South African Medical Journal,* 82: 237-240.

Brannon L. & Feiest J. (1992). Health Psychology: an introduction to behaviour and health (2nd ed.). California: Wadworth.

Brewer J. & Hunter A. (1989). *Multi-method research*. London: Sage.

Bronfenbrenner U. (1979). The Ecology of Human Development. Cambridge, Ma: Harvard University Press.

Brookins G. k. (1993). Culture, ethnicity, and bicultural competence: Implications for children with chronic illness and disability. *Pediatrics*, 91: 1051-1062.

Buhler G. (transl.) (1886). In: Miles M. (1995). Disability in an Eastern Religious Context: Historical perspectives. *Disability & Society,* 10,1: 49-69.

Burns P. (1989). In: Do Rozario L. (1997). Spiritually in the lives of people with disability and chronic illness: a creative paradigm of wholeness and reconstitution. Disability and Rehabilitation 19, 10, 427-434.

Byrne E.A., Cunningham C.C. & Sloper P. (1988). *Families and their children with Down's Syndrome: one feature in common.* London: Routledge.

Chermak G.D. (1991). A global perspective on disability: a review of efforts to increase access and advance social integration for disabled persons. *Int. Disabl. Stud,* 12: 123-127.

Chinnery B. (1991). 'Equal opportunities for disabled people in the caring professions: Window dressing or commitment?' *Disability, Handicap and Society,* 6,3: 253-258.

Cintas H. L. (1995). Cross cultural similarities and differences in development and impact of parental expectations on motor behavior. *Pediatric Physical Therapy,* 7: 103-111.

Clapton J. (1997). Disability, inclusion and the Christian Church: Practice, paradox or promise. *Disability and Rehabilitation*, 19,10: 420-426.

Coetzee D., Ferrinho P. & Rrinack S.G. (1990). Vaccination and nutritional status of children 12-23 month of age in Alexandra Township. Paper presented at the 9th Conference of Epidermiological Society of Southern Africa, East London.

Coetzee D., Ferrinho P. & Rrinack S.G. (1991). Nutritional status of children in Alexandra. Unpublished report, Alexandra Health Centre and University, Johannesburg.

Cornielje H.,Ferrinho P. Coetzee D.& Reinack S.G. (1993). Development of a community base rehabilitation program for a poor urban area in South Africa. *Journal of Comprehensive Health CHASA,* 4,2: 26-32.

Cuba E.G. & Lincoin Y.S. (1985). *Effective evaluation.* London: Jossey – Bass Publication.

Cusack C.M. (1997). Graciosi: Medieval Christian attitudes to disability. *Disability and Rehabilitation,* 19,10: 414-419.

Dasen V. (1988). Dwarfism in Egypt and classical antiquity: iconography and medical history, Medical History, 32, 253-276.

Dennill K., King L., Lock M. & Swanepoel T. (1995). *Aspect of primary health care.* Johannesburg: Southern Books.

Denzin N.K. (1970). *The research act in Sociology: A theoretical introduction to sociological methods.* London: Butterworths.

Devlieger P. (1995). Why disabled? The cultural understanding of physical disability in African society. In disability and Culture (edited by Ingstad B. & Whyte S.R.), 94-105. Berkeley: University of Calfornia Press.

Dexter L.A. (1970). *Elite and specialized interviewing.* Evenston: Northwestern University Press.

Dillard M., Andonian L., Flores O.,Lai I., MacRae A. &Shakir M. (1992). Culturally competent occupational therapy in a diversely populated mental health setting. *American Journal of Occupational Therapy*, 46: 721-726.

Disability Awareness in Action (1997). Disabled Children: Life and Development. Newsletter 55.

Donald D. (1994). Estimation of the incidence of special education need in South Africa. Working paper for National Education Policy Investigations Support Services. University of Cape Town.

Dorner S. (1975). The relationship of physical handicap to stress in families with an adolescence with spina bifida. *Developmental Medicine and Child Neurology,* 17:765-776.

Drews R.S, Foster G. & Chituna J. (1996). Cultural practices associated with death in the North Nyanga District of Zimbabwe and their impact on widows and orphans. *Journal of Social Development in Africa,* 11, 1: 79-86.

Elliot H. (1997). Religion, spirituality and dementia: pastoring to sufferers of Alzheimer's disease and other associated forms of dementia. Disability and Rehabilitation, 19, 10, 435-441.

Erfort C. (1999). Disabled have ability to reach the top at work. *Cape Argus,* May p. 13. South African Press.

Fabrega H. (1972). The study of disease in relation to culture. Behav. Sci., 17, 183-201.

Faouch C.B. (1998). *Research at grass roots:A primer for the caring profession.* Pretoria: Van Schaik.

Fine M. & Asch A. (1988). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of Social Issues,* 44: 3-21.

Fishbein M. & Ajzen I. (1975). *Belief, attitude, intention and behaviour.* Massachusets: Addison-Wesley.

Fitzgerald J. (1997). Reclaiming the whole: Self, spirit and society. D*isability and Rehabilitation,* 19.10: 407-413.

Foster D. & Nel D. (1991). Attitudes and related concepts. In D. Foster and J. Louw-Potgieter (Eds.), *Social Psychology in South Africa* (pp.121-170). Johannesburg: Lexicon.

French S. (1993). A study of physiotherapy as an occupational group – with special reference to their role in research. MSc. Dissirtation, London University.

French S. (1993). *Practical research: A guide for therapist.* London: Butterworth - Heimemann.

French S. (1994). Attitudes of Health Professionals towards Disabled People: A Discussion and Review of the Literature. *Physiotherapy,* 80: 687-693.

Friedman R. & Gool B. (1999). A Place that can be hard to call home. *The South African Times.*

Galanti G.A. (1991). *Caring for patients from different cultures.* Philadelphia: University of Pennsylvania Press.

Gallagher J.J., Beckman P. & Cross A.H. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional children,* 50: 10-19.

Gething G. (1986). International Year of Disabled Persons in Australia: Attitudes and integration. *Rehab. Lit.*, 47,3, 66-70.

Gibbs J.T. & Huang L. n. (1989). *Children with color: Psychological interventions with minority youth.* San Francisco, CA: Jossey-Bass Publishers.

Goode D.A. (1979). The world of congenitally deaf-blind: toward the ground for achieving human understanding, in: H. Schwartz & J.Jacobs (Eds) Qualitative Sociology: a method to medness (New York, Free Press).

Gregory R.J. (1998). Ten years on and more: establishing programme of rehabilitation education: The New Zealand Case. *Disability and Rehabilitation,* 20,10: 385-390.

Gregory, R.J. (1997). Definitions as power. *Disability and Rehabilitation*, 19: 487-489.

Groce N. (1987). Research in disability cross-culturally. *Disabl Stud Q.* ,7: 1-49.

Groce N. (1990). Competative and cross-cultural issues. *Disabl Stud Q'* 10: 1-39.

Groce N.E. & Zola I.K. (1993). Multicultural Chronic Illness, and Disability. *Pediatrics,* 91,5:1048-1055.

Gross R.D. (1987). Psychology: The science of mind and behaviour, Edward Arnold, London.

Hale L.A. & Wallner P.J. (1997). The challenges of service provision in South Africa for patient with hemiplegia. *Physiotherapy,* 82, 3: 156-158.

Hammond-tooke D. (1989). Rituals and medicines: Indigenous healing in South Africa, 53-73. Johannesburg: AD Donker.

Helander E. (1992). Disabled people in the developing countries: Situation analysis. The forum on co-ordination of rehabilitation programmes. Geneva: United Nations development programme.

Herskovits M.J. (1955). In Brookins G.K. (1993), Culture, ethnicity, and bicultural competence: Implications for children with chronic illness and disability. *Pediatrics,* 91: 1051-1062.

Hicks C.M. (1995). *Research for physiotherapists. Project Design and analysis.* (2nd ed.). Churchill Livingstone.

Higgins P. (1992). *Making disability: Exploring the social transformation of human variation.* Chicago IL: Charles C. Thomas.

Homan R. (1991). *The ethics of social research,* Longman, London.

Howell S.C. (1973). Psychiatric aspects of habilitation. *Pediatric clinics of North America,* 20: 203-219.

Humphries S. & Gordon P. (1992). *Out of sight: the Experience of Disability 1900-1950.* Northcote House, London.

Imrie R. (1997). Rethinking the relationship between disability, rehabilitation and society. *Disability and Rehabilitation,* 19: 263-271.

Ingstad B. (1998). *Community-Base Rehabilitation in Botswana: The myths of hidden disabled.* New York: The Edwin Mellen Press.

International Center for the Disabled (1986). *The ICD Survey of Disabled Americans: Bringing Disabled American into the Mainstream.* New York: L. Harris & Associates.

Jackson H. & Mupedziswa R. (1988). Disability and rehabilitation: Beliefs and attitudes among rural disabled people in a Community-Based Rehabilitation scheme in Zimbabwe. *Journal of social Development in Africa,* 3, 1: 21-23.

Johnston M. (1977). Folk beliefs and ethno cultural behavior in pediatrics. *Nurs Clin North Am.,* 12: 77-84.

Johnston M., (1996). Model of disability . Physiotherapy and Practice, 12: 131-141.

Kallio V. (1982). Medical and social problems of the disabled. Euro Reports, World Health Oganization, Copenhagen.

Kalyanpur M. (1999). Special Education Episteology as a product of Western Culture ; Implication for non-western families of children with disabilities. *International Journal of Rehabilitation Research*, 22: 111-118.

Katzenellenbogen J.M., Joubert G. & Abdool Karim S.S. (1997). *Epidemiology: A manual for South Africa.* (1st ed.), South Africa: Oxford University Press.

Keir N. (1970). Staff expectations for disabled persons. *Rehabilitation Counseling Bulletin*, 14: 85-94.

King D. (1999). Tackling poverty for a better city. *Cape Times*.

Kleinman A. Eisenberg L. & Good B. (1978). Culture illness and care: clinical lessons from anthropology and cross culture research. Annals of internal Medicine, 88, 16-22.

Kleinman A. M. (1975). Exploring models in health care relationship, in Health of Family (National Council for International Health Symp) Washington D.C., NCHI, pp. 159-172).

Knutson L. M., Leavitte R.L. & Sarton K.R (1995). Race, Ethnicity and other Factors Influencing Children'S Health and Disability. *Pediatric Physical Therapy,* William and Wilkins.

Kolobe T.H.A. (1995). Perspective: Serving underserved children: A South African perspective. *Pediatric Physical Therapy,* Williams and Wilkins.

Kopparty S.N.M. (1994). Problems acceptance and social inequality: A study of deformed leprosy patients and their families. *Leprosy Review,* 66: 239-19.

Leavitt R. L. (1992). *Disability and Rehabilitation in Rural Jamaica: An Ethnographic Study.* London and Toronto: Associated University Presses.

Leedy P.D. (1993). Practical research. Planning and design. (5th ed.): MacMillian Publishing Company. United States of America.

Legge V. (1982). *Disability in Cultural Context.* Sydney: Cumberland College of Health Sciences.

Lerer L.B., Matzopoulos R.G. & Phillips R. (1997). Violence and injury mortality in the Cape Town metropole. *South African Medical Journal*, 87: 298-301.

Locust C. (1988). Wounding the spirit: Discrimination and traditional American Indian belief system. *Harvard Educational Review,* 58,3: 315-329.

Longmore P.K. (1987). Uncovering the hidden history of people with disability. *Review of American History*, 15: 355-364.

Loveday M. (1993). Dissertation on an evaluation of SACLA rehabilitation workers project in Cape Town South Africa. University of Cape Town.

Marks D. (1997). Who needs models?. *Disability and Rehabilitation,* 19: 492-495.

Marshall C. & Rossman G. (1989). *Designing Qualitative Research.* Newbury Park: Sage Publication.

McCoy G.F., Johnstone R.A., Nelson I.W. & Duthie R.B. (1989). A review of fatal road accidents in Oxfordshire over a 2-year period. Injury, 20, 65-68.

McCubbin H.I., Thompson E.A. Thompson A.I., McCubbin M.A. & Kaston A.J. (1993). Culture, ethnicity, and family: Critical factors of childhood chronic illness and disability. *Pediatrics,* 91, 5:1063-1070.

Mckinney B. & Peterson R.A. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Psychology,* 12: 133-149.

McPherson M. (1993). General comments. Pediatrics, 91,5:1023-1024.

Mead M. (1955). *Childhood in Contemporary Culture.* Chicago IL: The University of Chicago Press.

Mechanic D. (1968). *Medical Sociology: a Selective View.* New York: Colombia University Press.

Mejia A. (1987). Health manpower out of balance. *World Health Stat. Q.*, 40: 335-348.

Meyer D.J. (1986). Fathers of handicap and their families. In Fewell R.R., Vadasy P.F. (Eds), *Family of Handicapped Children: Needs and support across lifespan.* Austin, TX: Pro. Ed.

Meyers C. (1992). Hmong children and their families: Consideration of cultural influence in assessment. *The American Journal of Occupational Therapy,* 46:737-744.

Miles M. (1995). Disability in an Eastern Religious Context: Historical perspectives. *Disability & Society,* 10,1: 49-69.

Miles M. B. (1979). Qualitative data as an attractive nuisance: The problem of analysis. *Administrative Science Quarterly,* 24,4: 590-601.

Miles M.B. & Huberman A.M. (1994). *Qualitative data analysis.* London, Sage Publications.

Ministry in the Office of the President (1995). *Integrated National Disability Strategy: Discussion paper*. South Africa.

Mitchell R.A., Zhou D., Lu Y. & Watts G. (1993). Community-Based Rehabilitation: Does it change community attitudes towards people with disability?. *Disability and Rehabilitation*, 15,4: 179-183.

Molteno C. (2001). *Aetiology of intellectual disability and its implications for 'prevention: Prevention of mental handicap – A world view*. CAMHADD Conference: Cape Town.

Moore E. (1985). Ethnicity as a variable development. In: Spencer M.B, Brookins G. K. & Allen W.R., (Eds.). *Beginings: The social and affective development*

of black children. Hillsdale, N.J.: Lawrance Erlbaum Associates, pp.101-116.

Motiwana M., Walters S. & Groener Z. (1989). *The struggle for democracy. A study of community organizations in greater Cape Town from 1960-1988.* CACE: University of Western Cape.

National Health Plan for South Africa (1994). Prepared by the ANC Health Department with the technical support of WHO and UNICEF. Johannesburg: ANC.

Ngubane H. (1977). *Body and mind in Zulu medicine: An ethnography of health and disease in Nyaswa – Zulu thought and practice.* London: Academic Press.

O'Toole B. (1988). Community-based rehabilitation; reaching the unreached. *International Journal of Special Education*, 3,1:21-37.

O'Toole B.J. (1991). Guide to community-based rehabilitation services. *Guides for special education.* France: UNESCO.

Okediji F. (1973). 'Theoretical and methodological critique of survey of knowledge, attitudes and practise of family planning in Africa'. *International Review of Modern Sociology,* 3: 1-11.

Oliver M. (1990). *The politics of disablement.* London: Macmillan.

Oppenheim A.N. (1992). Questionnaire design, interviewing and attitude measurement (2nd ed.). London: Printer publishers.

Page R. M. (1984). *Stigma.* London: Routledge and Kegan Paul.

Paris M. J. (1993). 'Attitudes of medical students and health care professionals towards people with disabilities', Archives of Phydical Medicine and Rehabilitation, 74: 818 – 825.

Parry A. (1991). Physiotherapy and methods of inquiry: Conflict and reconciliation. *Physiotherapy,* 77, 7: 435-438.

Partridge C. & Barnitt R. (1986). Research Guidelines: a Hand book for therapists, Heinemann, London.

Peace S.M. (1993). Negotiating. In Shakespeare P., Atkinson D. and French S. (Eds.), *Reflection on Research in Practice,* Buckingham: Open University Press.

Pedersen F. A. (1980). The father-infant relationship: observational studies in the family setting. New York: Praeger.

Primeaux M.H. (1977). American Indian health care practices: A cross cultural perspective. *Nursing Clinics in North America,* 112: 55-65.

Quine L. & Pahl J. (1989). Parent of severely mentally handicapped children: Marriage and stress of caring. In Robert Chester and Paul Dival (Eds). *Mental health illness and handicap in marriage.* Rugby: National Marriage Guidance Council.

RDP (1994). *The reconstruction and development programme.* Johannesburg: ANC, Umanyamo.

Reber A.S. (1985). Dictionary of Psychology. Penguin Books. Harmondsworth.

Rees H., Buch E, Groeveld H., Neething A., Ferrinho P. (1989). *Immunization rates and reasons for incomplete immunization in Alexandra Township.* Paper presented at the 8th Conference of Epidermiological Society of Southern Africa, Durban.

Rubin A. & Babbie E. (1989). *Research methods for social work,* Belmont, CA.: Wadsworth Publishing.

Schlebusch L. (1990b). *Psychological concepts in disease and health, Clinical Health Psychology: a behavioral medicine perspective.* Halfway House: Southern Book.

Schneider J.W. (1988). Disability as a moral experience: epilepsy and self in routine relationships, Journal of Social Issues, 44:63-78.

Schnetler J. (1989). Principles of constructing questions and questionnaires. In Schnetler (Ed.), *Survey methods and practices*. Pretoria: Human Science Research Council, (pp.44-99).

Schuerman J.R. (1983). *Research evaluation in the human services.* New York: Free Press.

Selway D.A. (1997). Editorial. *Rehabilitation and Disability*, 19, 10: 396-397.

Simeonsson R.J. (1991). Early prevention of childhood disability in developing countries. *International Journal of Rehabilitation Research,* 14:1-12.

Slabbert C.F. (1992). A new South Africa – a new health care strategy. *South African Medical Journal,* 82: 388-391.

Slaughter-Defoe D.T., Nakagwa K., Takanishi R. & JohnsonD.J. (1990). Towards a cultural/ecological perspective on schooling and achievements African and Asia- American children. *Child Development,* 61: 263-383.

Smart J.F. & Smart D.W. (1991). Acceptance of disability and the Maxican American. *Culture, Rehabilitation Counseling Bulletin*, 34, 4: 357-367.

Soder M. (1990). Prejudice or ambivalence? Attitudes toward persons with disabilities. *Disability, Handicap & Society*, 5, 3: 227-241.

Stone L. & Campbell J. (1984). The use and misuse of survey in international development: An experiment from Napal. *Human Organization*, 43: 27-37.

Stricklin M.L.V. (1997). Community-based care: back to future. *Disability and Rehabilitation,* 19, 4: 158-162.

Tennant A. (1997). Model of disability: A critical perspective. *Disability and Rehabilitation,* 19: 478-479.

The South African Medical and Dental Council (1995). Memorandum and questionnaire for postgraduates (specialists). *Education and training in medicine.* Pretoria: SAMDCA.

Thompson C.M., Buccimazza S.S., Webster J., Malan A.F. & Molteno C.D. (1993). Infants of less than 1250 grams birth weight at Groote Schuur Hospital: Out come at 1 and 2 years of age. *Pediatrics,* 91: 161-968.

Thorbun M.J. & Marfo K. (1990). *Practical approaches to childhood disability in developing countries: Insight from experiences and research.* Newfoundland, Canada. Project Seredec.

Tsai S.P., Lee E.S. and Hardy R.J. (1978). In: McCoy G.F., Johnstone R.A., Nelson I.W. & Duthie R.B. (1989). A review of fatal road accidents in Oxfordshire over a 2-year period. Injury, 20, 65-68.

Venters M. (1981). Familial coping with chronic and severe childhood illness: the case of cystic fibrosis. *Social Science and Medicine*, 15A: 289-297.

Wade D.T. (1996). Epidemiology of disabling neurological disease: how and why disability occur? J*ournal of Neurology, Neurosurgery and Psychiatry*, 61: 242-249.

Walburn J.N. (1988). Black children care practices in the Midwest. *Pediatrics*, 82:789-790.

Werner D.B. (1988). *Disabled Village Children. A guide for community health workers, rehabilitation workers, and families.* Palo Alto: The Hesperian Foundation.

Westbrook M.T., Legge V. & Pennay M. (1993). Attitudes towards disabilities in multicultural society. *Social Science Med.*, 13, 5: 615-623.

White paper (1997). *Transformation of the health system in South Africa: (no. 17910.)* Department of Health.

WHO & Medical Commission of Rehabilitation International (1985). *Better opportunity for disabled people.* Reporting meeting: Wessenburg.

WHO (1982). World Health Organization report interregional consultation In Srilanka. *Community-Based Rehabilitation* (RHB/IR/82.1). Geneva.

WHO (1990).Global Programme on AIDS: Social Behavioural Reseach Unit. Research Package: *Knowledge, attitude, beliefs and practices on AIDS* (KABP). Geneva.

WHO (1980. Reprint 1993). *International Classification Impairments, Disabilities and Handicaps.* Geneva.

Wikler L.M. (1986). Periodic stress of families of older mentally retarded children: An exploratory study. *American Journal of Mentally Deficiency*, 90: 703-706.

Zeitlin A.G. & Turner J.L. (1985). Transition from adolescence to adulthood: perception of mentally retarded individuals and their families. *American Journal of Metal Deficiency* 89: 570-579.

Zola I.K. (1972). The concept of trouble and sources of medical assistance. Soc. Sci. Med., 6, 673-679.

The Superintendent, 17.07.99

Tygerberg Hospital,

Red Cross Children's Hospital,

Rondebosh. 7701.

Dear Sir/Madam,

Re- collection of data for the MSc Physiotherapy Program

Title: Cultural beliefs towards disability : Their influence on rehabilitation

Supervisor: 1. Mrs Mary Faure, Senior lecturer. Department of Physiotherapy. University of Stellenbosch. Tel. 938 9497.

2. Sheena Irwin-Garruthers. Former head of the Department of Physiotherapy . University of Stellenbosch. Tel. 557 6200.

Principal Investigator: Tseleng Leonea Masasa. Dip. Physio. Bsc Honours Physiotherapy. Principal Physiotherapist, Ministry of Health, Lesotho.

I am doing the MSc program at the University of Stellenbosch on the above mentioned title. It has come to the attention of therapists that the insensitivity and lack of awareness of culture can make rehabilitation difficult. The point of view of the clients and the therapists may differ when it comes to decision making on rehabilitation. It is important that medical professionals are aware of cultural differences and beliefs, and their possible influence on the outcome of rehabilitation. Data need to be collected from Red Cross Hospital and Tygerberg Hospital. I therefore, request you to grand me permission to collect the data from the Physiotherapy Department in your hospital for this research project.

The sample will consist of systemically selected biological caregivers of physically disabled children from the out-patients at Red-Cross Hospital and Tygerberg Hospital. The family has been recognised as a critical social unit mediating tradition and culture. It is assumed that the information elicited from them can be informative when it comes to the future planning of treatment/rehabilitation intervention of the physically disabled children.

Confidentiality and research ethics will be followed throughout. The copies of the research will be available at the library and physiotherapy department at the University of Stellenbosch.

Your assistance will be highly appreciated. Thank you for your co-operation.

Yours faithfully

TSELENG LEONEA MASASA.

Department of Physiotherapy

Faculty of Medicine

P.O. Box 19063, Tygerbeg 7505.

UNIVERSITY OF STELLENBOSCH.

DEPARTMENT OF PHYSIOTHERAPY.

Investigator: T.L. Masasa - Tel: 3645500/2

Supervisor 1: Mrs. M Faure.

Supervisor 2: Mrs. S. Irwin-Carruthers.

Questionnaire on knowledge, attitudes and believes towards people with disability.

The aim of this questionnaire is to obtain information from caregivers of disabled children about their knowledge, attitudes and believes towards disability so we could determine their effects on rehabilitation of those children with disability.

You will notice that we do not ask for your name or your child=s name. There are also no wrong answers. Al the answers are important and will help us to get the information which will assist us to give an effective rehabilitation intervention in the area of disability. For this reason we ask you to be entirely free and honest in answering the questions.

Do you understand what the proposed research is about?

Yes ~ No ~

If no, do you have any questions?

Now that I have answered your questions, are you willing to participate in my study?

Yes ~ No ~

Thank you for agreeing to talk to me and I have to respect your wish not to want to participate in my study.

We sincerely appreciate the time you will spend on this questionnaire and thank you for your participation and contribution in this study.

UNIVERSITY OF STELLENBOSCH

UNEVERSITEIT VAN STELLENBOSCH

Tygeberg Campus Tygerbergkampus

P.O. Box 19063.Tygerberg 7505. S.A. Posbus 19063.Tygerberg.7505. S.A.

QUESTIONNAIRE ON CULTURAL BELIEFS TOWARDS DISABILITY: THEIR INFLUENCE ON REHABILITATION.

It has come to the attention of medical professionals that to successfully deliver effective quality services, one has to understand the culture of the client one is dealing. This is especially relevant in setting rehabilitation goals with persons with disability. I would like you to help me with my project. Therefore, you will be asked questions on your understanding and beliefs on disability. Your sharing of your feeling and knowledge on disability could have important implications for the future planning of rehabilitation of the disabled persons.

You will notice that you don't have to tell me your name nor the name of the child. The only thing needed is to answer every question as honestly as possible. It is your opinion that is wanted. For this reason you are kindly asked to be entirely honest in answering the questions.

Please rest assured that all the information you will give will be treated with

confidentiality. All the information will be added together so that no person can be identified. When the study is completed the report will be given to the Tygerberg Hospital, Red Cross Hospital and the University of Stellenbosch. If you are interested in the results you are free to ask the authorities of the above mentioned areas for the report.

If you have any questions on the ongoing research please feel free to contact me at the above address.

I sincerely appreciate the time you will spend in answering the questions and I thank you very much for your participation and contribution in this research project.

.....

Tseleng L. Masasa.

STUDENT: MASTERS DEGREE IN PHYSIOTHERAPY.

PART I

DEMOGRAPHIC DATA OF PARENTS/CAREGIVERS

Date..... Cultural group.....

TO BE ANSWERED BY ONE PARENT OR A RELATIVE OF THE CHILD.

(Please fill in the space provided and answer every question).

1 . Age

1-[20-30], ☐

2-[31-40], ☐

3-[41-50], ☐

4-[51-60], ☐

5-[60 and upwards]. ☐

2 . Gender

1-Female ☐

2-Male ☐

3 . Language

1-English ☐

2-Afrikaans ☐

3-Xhosa ☐

4-Zulu ☐

5-Tswane ☐

6-North Sotho ☐

7-South Sotho ☐

8-Venda ☐

9-Pedi ☐

10-Tsonga ☐

11-Ndebele ☐

12-Swati ☐

13-Other – (Specify)..... □

4 . Religion

1-Christian □

2-Moslim □

3-Hindu □

4-No religion □

5 . Marital status

1-Married □

2-Single □

3-Divorced □

4-Widow □

6 . Number of children

1-1 – 2 □

2-3 - 5 □

3-6 –10 □

4-More □

7 . Highest level of education

1-No education □

2-Primary □

3-High school □

4-Tertiary □

8 . Relationship with the child

1-Mother □

2-Father □

3-Grand mother □

4-Grand father □

5-Aunt □

6-Uncle □

Occupation.....

PART II

DEMOGRAPHIC DATA OF THE DISABLED CHILD.

1 . Age

1-[1-5], □

2-[6-10], □ ☐

3-[11-13], □

2 . Gender

1-Female □

2-Male □ ☐

3 . Nature of disability:

1-Partially dependent □(capable of performing at least one personal care i.e eat, wash and dress independently) ☐

2-Totally dependent □(not capable of performing any activity).

dagnosis.....

PART III

KNOWLEDGE, BELIEFS AND ATTITUDES TOWARDS DISABILITY:

1 - Have you ever heard or read about disability?

Yes No not sure if yes, when? .....

.....

.....

.....

2 - Is there another name for a person with disability in your own language?

Yes No do not know If yes, specify.....

.....

.....

.....

....

.....

...

3 –Have you ever seen anyone with a disability?

Yes No not sure If yes,

where?.....

.....

.....

.....

.....

.....

4 – Do you have anyone with disability among your relatives ?

Yes No do not know If yes, specify the relation.....

.....

.....

.....

.....

.....

.....

5 - Do you know anyone else with a disability who is not your relative?

Yes No not sure

.....

.....

..... 6 - Do you have any idea of what causes disability?

Yes No not sure If yes, explain.....

.....

..

.....

....

.....

....

7 - Do you think disability runs in families (inherited)?

Yes No Do not know Explain.....

.....

....

.....

....

8 - Do you think disability is contagious?

Yes No Do not know

Explain.....

.....

.....

.....

.....

I will read a number of statements and questions to you and I would like you to indicate how much you agree or disagree with each of the statements or questions.

9 - Disability is a man made disease.

Strongly agree Mildly agree Mildly disagree Strongly disagree do not know ,

Explain.....

....

.....

.....

.....

.....

10 - Disability is a disease from God.

Strongly agree Mildly agree Mildly disagree Strongly disagree do not know

Explain.....

....

.....

.....

.....

.....

11 – Is it a good idea to have hope that your disabled child will be cured?

Very bad idea bad idea good idea very good idea □do not know □not sure □

Explain.....

...

.....

.....

.....

.....

12 - You always feel sorry when seeing someone with disability.

Strongly agree Mildly agree Mildly disagree Strongly disagree do not know ,

why?.....

....

.....

.....

13 - Besides needing help with some physical activities, disabled people are different from other people.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

why?.....

.....

.....

.....

.....

14 - Your disabled child should not marry.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know Yes

No Why?.....

.....

.....

15 - You are afraid of disabled people.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know .

Why?.....

....

.....

.....

.....

.....

16 - Your child who is not disabled should not marry a disabled person.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know .....

.....

.....

.....

.....

.....

....

17 - People with disability should not have children.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

why?.....

...

.....

.....

.....

.....

18 - If you happen to be the manager of a company, you would not employ disabled persons in your company.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know explain

why?.....

.....

.....

.....

.....

19 - People with disability should not be allowed to be in charge of the company.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

why?.....

.....

.....

.....

.....

.....

.....

20 - Families having disabled people should completely hide them.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

why?.....

....

.....

.....

.....

.....

21 - Disabled persons should associate with the other members of the community.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

why?.....

.....

.....

.....

.....

.....

22 - Persons with disability should not be allowed to use public transport.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know how should they

travel?.....

23 - If after seeing a doctor you are informed that your child cannot walk, talk or see, it is necessary to take the child for any other medical services.

Absolutely unnecessary unnecessary necessary very necessary do not know not sure . Why?.....

.....

.....

24 - It is a good idea to take the disabled child to other healers e.g. religious or traditional healers besides the western (hospital) healers (e.g. religious or traditional healer).

The worst idea bad idea good idea best idea do not know not sure .

Explain.....

....

.....

.....

25 - Parents of children with disability should have an opportunity to give an opinion and participate in the treatment of their disabled children.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

Explain.....

....

.....

.....

.....

.....

26 - What are the chances of taking your child for regular treatment?

Very good chance good chance small chance very small chance do not know not sure . Why?.....

.....

.....

.....

.....

27 - Disabled children should not attend school.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

Why?.....

....

.....

.....

.....

.....

28 - Disabled children should have their own schools.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

Why?.....

....

.....

.....

.....

29 -Is it a good idea for the parent of disabled children to participate in the planning of their children s education?

Very bad idea bad idea good idea very good idea do not know not sure

Why?.....

....

.....

.....

.....

30 - Disabled children should participate in sports.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

Explain.....

....

.....

.....

.....

31 - Disabled persons are inferior.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

Explain.....

....

.....

.....

.....

.....

32 – How much do your relatives like your disabled child?

Very much much dislike dislike very much do not know not sure

Explain.....

...

.....

.....

.....

.....

33 –How well does society help disabled people?

Very well well not well not very well do not know not sure .

Explain.....

.....

.... .

.....

.....

.....

.....

34 - Disability is not a disease from God.

Strongly agree Mildly agree Mildly disagree Strongly disagree do not know

Explain.....

....

.....

.....

.....

.....

35 - People with disability should have children.

Strongly agree mildly agree mildly disagree Strongly disagree Do not know

why?.....

...

.....

.....

.....

.....

36 - If you wake up in the morning and you find yourself a President of this country, what would you do for the disabled persons?